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ABSTRACT

Presented are the final reports of a two-part project designed to measure the effect of an intensive inpatient developmental program on 40 young multi-handicapped children (18-36 months old) and their parents. Part 1 describes a system developed and tested to record and analyze changes in child functioning. Reported are results from teacher-written logs and videotaped diagnostic sessions on the following dimensions: interaction with materials, awareness of the environment, social responsiveness, expressive communications, affect, gross motor and fine motor ability. (A coding manual is appended.) Among findings cited are that mental age was more meaningful than chronological age as a descriptor of status, and that age levels assigned to competent work with educational materials yielded the most relevant information for developmental assessment/prescription. Part 2 describes an analysis of open-ended, comparatively non-structured weekly interview sessions with parents of 20 of the children in Part 1. Results of complementary quantitative analyses are said to indicate that most parents were found to shift from an original emphasis on physical and language disabilities to consideration of other developmental aspects. Parental satisfaction with programmatic intent and implementation is documented, as well as the change in parents from a passive and "recipient" role to one of greater participation. It is noted that socioeconomic status and type and degree of disability of their children were not found to be related to parents' attitudes toward the program. (Author/CL)

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EVALUATION OF BEHAVIORAL CHANGE

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U.S. DEPARTMENT OF HEALTH,
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EDUCATION

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Study of Multi-Handicapped Young Children

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ABSTRACT

Part I: Study of Multi-Handicapped Young Children

Part I describes a system developed and tested to record and analyze changes in functioning in young multi-handicapped children (ages 18 to 36 months, $N = 40$) who were exposed to an intensive, in-patient developmental program. The two sources of data were the teacher-written log and videotaped diagnostic sessions, which included learning experiences presented and the child's responsive behavior. Dimensions specifically selected for study were dictated by the educational philosophy of the program: Interaction with Materials, Awareness of the Environment, Social Responsiveness, Expressive Communications, Affect, Gross Motor and Fine Motor Ability. A coding manual is appended.

The system extracted data concerning levels and change of functioning in dimensions over time. Dimensions were interdependent. Data were examined for the total group, subgroups, and individual children. Distinct subgroups were identified, but within-group variability was marked. Quantitative plus qualitative analysis of data on individuals yielded the most meaningful picture of status and change.

Chronological age was not related to functioning; mental age was more meaningful as a descriptor of status. Age levels assigned to competent work with educational materials yielded the most relevant information for developmental assessment/prescription.

Part II examines the interactional and reciprocal relationship between program and parents of 20 of the children studied in Part I.

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INTRODUCTION

"On admission to the Infant Program at the Institute of Rehabilitation Medicine (IRM), child X was medically diagnosed as 'congenital cerebral palsy, spastic diplegia type.' He was 30 months old and had been assessed as functioning at a mental age (MA) of approximately 13 months on sections of the Bayley Scales. X was severely delayed in motor development. Although able to roll independently from stomach to back or from back to stomach, he could not crawl, creep, or pull to standing. There was no evidence of sensory deficit. He exhibited mild to moderate involvement in his upper extremities, using both palmar and pincer grasp. X had some neuromuscular problems, which impinged upon his production of expressive speech as partially reflected in the evaluation of his language functioning on the level of a 6-month old child. The staff speech pathologist reported receptive functioning at 10 to 12 months."

The above is the typical information to be found in records and reports written upon admission about a young multi-handicapped child. Data are gathered by a variety of specialists in the field of handicapped children (medicine, psychology, physical therapy, occupational therapy, and speech pathology). Several questions arise: What kind of early intervention program should be designed for this child? Of what value will it be? What changes in his development can be expected from exposure to such a program? Of what value is a medical diagnosis, chronological age (CA) or MA to the teacher? Does it tell the teacher how or what to teach? On what areas of development shall the teacher concentrate? What types of goals for the child can be projected on the basis of these data?

These questions should lead the educator to attempt to define and describe the child in educational terms, using educational concepts. Assessment and study will, then, be directly connected to an educational habilitation program for children with translation of developmental objectives and support for their families. This concern for relatedness between the study of the child and the education of the child poses further questions. Can the teacher gather data that will be the basis of the study of the young multi-handicapped child? Will these data be amenable to quantification and statistical study? Will these data be of greater value in terms of teaching than an imprecise MA? Which and how many educational dimensions will be needed in order to define, categorize, and study the child? Will patterns of change emerge across time, and will such patterns have predictive significance for these multi-handicapped children? What role do the families play in this process of change? Can both the methodology of data collection and analysis be utilized in further studies of children and curriculum for "normal" populations of very young children?

These are but a few of the issues and questions to which we address ourselves in this report. Our approach has been to merge educational data and experience with psychological concerns for methodology and statistical rigor.

Theoretical Orientation

The basic point of view for both our education program and for our evaluation methodology has been and is unconventional in the field of "special education." Educationally we are aligned with those early childhood specialists who subscribe to the philosophy of teaching and studying the child holistically, i.e., the child in relationship to the total environment, which is viewed as including family, teachers, materials, etc. (Biber & Franklin, 1967). This is in sharp contrast to the many "deficit" approach programs, which are designed to compensate for individual and highly specific deficiencies (Northcott, 1971; Quick, Little, & Campbell, 1973; Sanford, 1974; Shearer, 1974). We believe that prescription and education must involve focus on more than development in narrow areas of dysfunction; they should extend and examine the child's capacity in each aspect of functioning (Gordon, 1975). This viewpoint, when carried to its logical conclusion, demands that facilities-environments be designed and that educational staff and evaluators be trained to nurture and value optimal child-teacher-environment interactions.

Our conception of the "classroom" environment, the educational program, and the research component are all rooted in a developmental-interaction point of view, specifically modified for this young multi-handicapped population. In this formulation, "developmental" refers to the emphasis on identifiable patterns of growth and modes of experiencing and responding that are associated with increasing chronological age; and interaction refers to the individual child's interaction with the environment" (Biber & Franklin, 1967, p. 7). Thus, emphasis is placed both on the "nature of the environment and on the patterns of the responding child" (Biber & Franklin, 1967, p. 7).

As developmentalists, we subscribe to far broader and more integrated educational goals that have been clearly articulated for the pre-school years by Biber, Shapiro, and Wickens (1971). These goals are:

- (1) To serve the child's need to make an impact on the environment with direct physical contact and maneuver...
- (2) to promote the potential for ordering experience through cognitive strategies...
- (3) to advance the child's functioning knowledge of his environment...
- (4) to support the play mode of incorporating experience...
- (5) to help the child internalize impulse control...
- (6) to meet the child's need to cope with conflicts intrinsic to his stage of development...
- (7) to facilitate the development of an image of self as a unique and competent person...
- (8) to help the child establish mutually supporting patterns of interaction (pp. 10-11).

We believe these goals are as relevant (although more difficult to achieve) in the process of educating handicapped children as they are in the process of educating normal pre-school age children. We do recognize, however, that each atypical child requires a sensitive and individualized program as well as a continuous readjustment of these generalized, broad, long-term goals.

Our experience has further suggested that there is a mutuality and reciprocity in development and that these concepts are as valid for the handicapped child as they are for the normal child. We view the affective life of the child as inextricably intertwined with the development of cognition. Thus, change in a child's emotional status may also be reflected by concurrent change in the child's social responsiveness and communicative skills, all of which are directly associated with the development of general cognitive abilities.

When one is faced with the question of evaluating an educational program based on those broad developmental goals, traditional evaluation models and strategies are clearly dissonant and inappropriate. A third-party evaluator could furnish more than adequate data, but how will these data feed back to educators (Zimiles, 1968)? Can this type of research act to stimulate educational thinking and thus come directly to influence the educative process? Will it tell educators about day-to-day variability and change, or will the evaluation scheme rely solely upon pre-post differences? Will standardized psychometric tests be employed (even if inappropriate -- see Shapiro, 1973)? Will discrete skills be examined through the use of checklists, or will growth and change in different areas of development be viewed as interdependent?

Each individual child's developmental status is the composite of a variegated pattern of growth, development, and change across the many individual but interacting dimensions. Documenting growth and change is, therefore, even more difficult than it is in the case of the young "normal" child. Despite the obvious difficulty and complexity of these problems, consideration of all these questions led to the development of a methodology for the study of a multi-handicapped population of children, based on and derived from naturalistic observation by educators. The product of this examination could result in more realistic and viable links between research and program. We have examined the child within the context of the program's goals. Thus, the child is studied in terms of the actuality of his relationship to his environment. We would agree with MacDonald (1974) that "the goals... are the crucial and significant aspects of the evaluation process, not the process of measurement..." (p. 6).

We have continually been aware of some of the realistic constraints on our findings and conclusions. One such constraint is the excellence and experience of our educational staff (which has generated the majority of the data) as well as the low teacher-to-child ratio (2/4). It can be questioned whether comparable data could be obtained in other settings with different levels of staff competence. One common problem in the evaluation of any educational program is that of assessing change. Each child has, in a sense, acted as his own control. Finally, we view any change in a child on program as the result of multiple determinants. Teachers, parents, therapists, as well as maturation, all contribute to the child's growth and development. It would, therefore, be naive to attribute differences in functioning to any one aspect of the program alone. We clearly recognize the multiple-factor influence in this setting.

A full description of the program will precede the method, results, and discussion of data on children. Data on parents have been treated separately from an anthropological perspective, with its own method, results, and discussion sections. (See Part II for data on parents.)

The Program

The Infant Program was begun in 1969 (Grant No. OEG-O-9-42035-41603(619)) as a downward extension of an existing educational program (initiated in 1962) for pre-school age children serviced in the Pediatric Division of IRM (Gordon, 1969).

The Children/The Subjects

At any one time only four very young children (18 months to 3 years of age) are "on program" in the infant school. The average stay on this program is 3 months. Approximately 15 infants per year are exposed to this intensive stimulation program. The 40 subjects of this study were children admitted to this special project during the years 1972 - 1975.

The Physical Setting

The physical setting for this study is a specially designed and equipped room within the Pediatric Division of the Institute of Rehabilitation Medicine, New York University Medical Center. Since conventional environments do not offer the opportunity for optimal action or interaction by severely handicapped children with orthopedic impairment, with absent or abortive limbs, or for those children whose neurological disability interferes with perceptual and spatial organizations, specific considerations were given to these special needs in the design of the infant room. Handrails assist in independent ambulation; carpeted and tiled areas provide different tactile surfaces; and a bathroom scaled down for children enables these multiply handicapped infants to interact with their surrounding environment, despite restricted mobility and reduced stamina. In addition, clear plastic domes on each crib permit both freedom and safety for those children who can stand up and move about. Figure 1, Appendix III presents the layout of the infant room. Along one wall are low cabinets with tambour doors containing some of the more than 125 toys and educational materials (tasks) used in the infant room. The remainder of the equipment is stored above the children's clothing cubbies. Thus, in a confined space, approximately 15' x 15', all the daily needs for living and education for four infants can be met.

Observation and recording of on-going activities is possible through a windowed area of the adjoining nursing station through a one-way glass in the door and by means of a video camera mounted on the ceiling. Videotaping equipment is activated by remote controls and can be monitored from the adjacent nursing station.

Additional activities take place in an outdoor therapeutic playground designed to allow these children actively to experience water, sand, trees, and grass in a compensatory setting (Gordon, 1972).

The Educational Staff

In order to optimize the potential of these very young multiply handicapped children, the ratio of teacher to child was established as one to two. The qualifications of the teaching staff include in-depth knowledge of child development, sensitivity to the specialized needs of very young children, and an ability to develop and implement an ever-changing curriculum using a wide range of educational activities and materials. These skills are necessary in order to deal with the mosaic of behavioral and cognitive disturbances that are directly related to organic disorders and lack of neurological integrity as well as the emotional reactions concomitant with physical disability. The master teacher has been with the program from the service's inception and has been directly involved in the research component.

In addition to these two highly trained educational specialists, the infant room is staffed by a nurse's aide, who has been exclusively assigned to the care of these children. Her role of dressing, changing, and feeding these four children from 7:30 a.m. to 3:30 p.m. places her in a position to provide on-going emotional stability. Implementation of procedures is consistent with those goals delineated for each child after multi-disciplinary conferences.

Multi-disciplinary Therapeutic Staff

The therapists within the Pediatric Division play an important role within the Infant Program. A therapist in each department and a social worker are assigned to every child upon admission who work with the child, the teachers, and the family in the development of a therapeutic program.

The Daily Schedule

The daily schedule for each child incorporates the therapist's time scheduling plans within the general framework of the Infant Program. For all children the educational program is scheduled to run from 9:30 a.m. to 4:00 p.m., Monday through Thursday, and 9:30 a.m. to 11:30 a.m. on Fridays. Between 11:30 a.m. and 2:00 p.m. the children have lunch and nap. Therapists can schedule the child for individual 30-minute periods within this time frame. Each child, therefore, is involved with a specialized therapy for approximately $\frac{1}{2}$ to $1\frac{1}{2}$ hours per day. On occasion a therapist will conduct a group session, e.g., group language stimulation. (Sample schedule is found in Item 1, Appendix III.)

Parental Participation

Consideration and study have also been devoted to the parents' needs and to parental participation in the program. We view the parents/family of the child as an integral component of the educational program. Anxiety, rejection, and guilt are characteristically found in many families of

handicapped children (Bentovim, 1972; Boles, 1959; Kass, Sigman, Bromwich, & Parmelee, 1974; Wolfensberger, 1967). At the same time these parents have been said to be unrealistic about their children's status and prognoses (Boles, 1959; Tew, Lawrence, & Samuel, 1974; Wolfensberger & Kurtz, 1971). Conventional methods of attitude assessment through questionnaires (Boles, 1959; Cook, 1963; Gumz & Gubrium, 1972; Wolfensberger, 1971; Zuk, Miller, Bartram, & Kling, 1961), rating scales (Schaefer & Bell, 1958), and structured interviews (Birenbaum, 1971; Matheny & Vernick, 1969) did not appear to match well with the parents' active role in our program. We have, therefore, attempted to develop a methodology by which to assess parental status in terms of the realities and limitations of the Infant Program.

Parents are expected to and do participate one full day each week. They are active participants in the Infant Program, first observing the techniques and methods of the teachers and therapists and then working directly with their children. During the participation day the parent discusses the educational program with the teacher. These discussions include general goals and specific activities which can be implemented within the home. In-depth sessions with the Project Director enable the parent to share past experiences, present plans, and future expectations (see Part II, pp. 1 to 35 for the study of parent data). These sessions also present an opportunity for the parents to raise concerns related to other services on the pediatric floor.

As the parent follows the child through the daily program, there is an opportunity to discuss each aspect of the program with the respective therapist. As the parent becomes acquainted and more comfortable with specialized techniques and means of educational stimulation, the child's program can be effectively extended at home over the weekend.

Program Procedures

Referral Procedures

The major source of referrals to the Infant Program is through the Clinical Director of the Children's Service and other medical staff connected with IRM, New York University Medical Center and specialized programs (Spina Bifida Clinic, Rubella Project, Amputee Clinic, etc.). This comprises 70% of our children. The remaining children (30%) are referred by other agencies (United Cerebral Palsy, 11%); by private pediatricians, 10%; and through contacts made directly by the parents. These children have all come from the Greater New York Metropolitan area, which is to be expected, when one considers that parent participation is an integral and required part of the Infant Program's admission policy.

Screening and Admission Procedures

Prior to admission to the Infant Program, the child receives a comprehensive medical and educational evaluation. This process permits a thorough assessment of the status and needs of the child and family.

The educational evaluation (screening) consists of a 20- to 40-minute videotaped session, during which the Project Director presents the child with approximately 10 tasks (educational materials). These tasks and activities are selected utilizing prior knowledge of the child's chronological age, medical diagnosis, and type of motor disability. Degree of competence exhibited by the child in response to the first few materials offered enables the examiner to modify each succeeding task.

Following this session the Project Director meets with the parents to discuss initial impressions of the child's functioning. Actual admission to the program is based on these evaluations, on consideration of the potential effects of separation upon both child and family, and on the basis of a conference with the medical director and social worker to discuss physical potential to benefit from a habilitation program. (There is no minimum level of functioning required for admission; however, at times, other programs outside of IRM may be recommended to optimize the child's competencies.) The length of time between assessment and admission varies according to the needs of the family and the availability of a place in the program and the appropriateness of grouping a new fourth child with the other three infants already on program. Admissions are generally projected for a period of 3 months. The minimum amount of time between admission of new children is 2 weeks, allowing each child an adjustment period, during which time a master teacher can focus on problems related to separation.

Prior to admission the teaching staff and other personnel are informed of the child's functioning ability, medical diagnosis, and relevant factors of the family situation. On the day of admission the parents meet with the Project Director, teacher, and the social service staff. They remain with the child throughout the entire first day. Each parent is assigned a day to participate during the week; however, if needed, parents will be asked to spend additional time in the infant room during this first transitional week.

The first 2 weeks serve as a period for intensive multi-disciplinary evaluation. During the first week an individual from each of the related disciplines -- physical therapy, occupational therapy, speech pathology, and psychology -- come to the room to meet and observe the child. Actual evaluations are initiated and completed within the classroom during the second week.

In a multi-disciplinary conference at the end of this 2-week period, the results of testing and evaluation and the clinical impressions of staff members from each discipline are presented and discussed. These discussions yield a specially designed program for each child designating the amount of time to be devoted to each therapy. Information relevant to establishing the education programs and goals evolve. Each therapy formulates its own short-term goals.

Educational Goals

Individualized educational goals are first delineated. These goals are central to the design of a curriculum for each child in the Infant Program.

Educational goals reflect the on-going interaction between child and teacher and are established at weekly teacher conferences and incorporate the clinical impressions and goals of the various disciplines. For each child on program there are from five to eight goals which vary from generalized plans (e.g., extending sensory experiences) to highly specific activities (e.g., form discrimination by inserting cylinders in a form box). (See Item 2, Appendix III, for sample sets of goals.) Based upon the child's performance during the following week, a particular goal may be modified (extended or simplified), deleted (because it proved to be above or below a child's competence), or incorporated within the teacher's general plans. Some goals are, therefore, not specifically listed (e.g., parallel play with a particular child), if these goals become a routine.

Re-evaluation Procedures

Greater consistency of goals and program is made possible through bi-monthly educational conferences of teachers and therapists. Each discipline reports on the child's progress and on its own short-term goals for the child. At monthly conferences directed toward medical needs of the child (e.g., prescription of eye consultation, decision for orthopedic surgery), the disciplines of medicine, education, psychology, social services, nursing, speech pathology, physical therapy, and occupational therapy give in-depth reports related to the child's status.

Discharge Decision

At the end of 3 months the child's and family's needs and progress are re-evaluated. A significant spurt of growth in any area of functioning (e.g., educational program, physical therapy) may be a factor in the decision to maintain the child on program for another 2 to 4 weeks. Other considerations might be the need to find a follow-up program for the child or waiting for a medical problem to stabilize (e.g., determine the proper level of medication to control seizures).

The most frequent pattern has been discharge at the end of 3 months followed by admission either to the out-patient Infant Program at IRM or to a local agency. Parents are involved in the final referral decision. They meet with the Project Director, therapists, and doctors to outline goals, activities, and exercises which can be implemented at home to maintain the progress made during the program. If plans include immediate referral to another agency, then meetings are set up with the new agency. Whenever possible or requested, this includes visits of IRM staff members to the new program both prior to and following admission, with reciprocal visits of the educational staff of the new agency to IRM.

METHOD

Subjects

Demographic Data

This study focuses on 40 children who were enrolled in the in-patient Infant Program at IRM. These children ranged in age from 19 months to 40 months at time of admission and were comprised of 17 females and 23 males. Table 1, Appendix IV presents complete demographic data. For purposes of uniformity each child in the study was assigned a letter(s) referring to sequence of entry into the program.

Both MA obtained on admission as well as IQ's derived from these MA's showed a wide range, with MA ranging from 3 to 29 months and IQ ranging from 11 to 93. It is important to note that many of these scores, moreover, represent approximations, as existing standardized infant scales are usually inappropriate for assessing a multi-handicapped population. The MA's were often obtained by employing a composite of several modified tests and clinical interpretation based on extended observation. Figure 1, p. 10 depicts this spread of scores further modified by sex.

In terms of demography the population under study represents a broad cross-section of the general population (for analysis of socioeconomic status see Figure 2, p. 11, and for analysis of ethnic background see Figure 3, p. 12). Twenty-five percent of families ($N = 10$) of children studied were on public assistance. Using income, occupation, and education as classificatory variables (Langer & Michael, 1963), 18% ($N = 7$) of the families were of low socioeconomic status (SES); 7% were high SES ($N = 3$), with the remaining families in the middle range. Ethnic distribution was broad, with 32% of Hispanic origin ($N = 13$), 20% Black Americans ($N = 8$), one Chinese family, and the remaining families (45%) White Americans ($N = 16$).

Medical Diagnoses

The divergent nature of the children's level and area of dysfunction is not adequately delineated by broad medical descriptors. Figure 4, p. 13, presents the four predominant medical diagnostic categories (cerebral palsy, spina bifida, delayed development, and brain damage), modified by severity of motor impairment. The majority of children (70%) were diagnosed as "cerebral palsy". These children have handicapping conditions with varying patterns of motor dysfunction (spasticity, ataxia, etc.), location of disability (hemi, quad, etc.), and severity (paresis or plegia). Diagnostic category alone is not expected to predict patterns of functioning for these children. This is considered in the analysis of the data. Table 2, Appendix IV, presents expanded medical diagnoses.

At times the child's handicapping condition is associated with a chronic medical problem which requires constant medication and treatment. Of the 40 children in the study, only six have been heavily medicated (usually to prevent seizures). The majority (75%) required no medication or only some medication, usually a small dosage once a day (four children). For some children, therefore, changes in type and quantity of medication might have temporarily interfered with the child's optimum performance. This is considered in the analysis of the data.

CHRONOLOGICAL AGE (C.A.) AND MENTAL AGE (M.A.) AT ADMISSION N=40

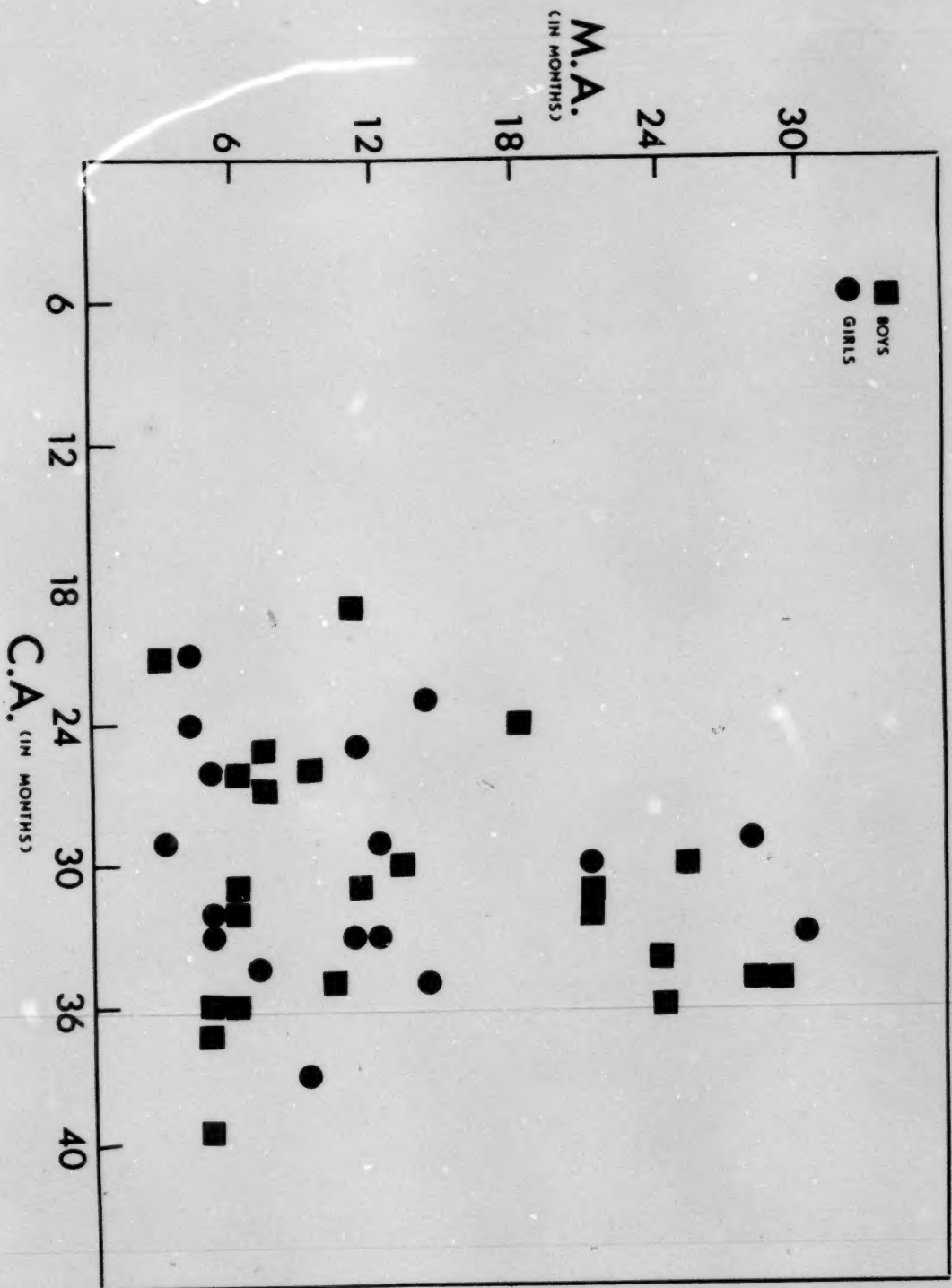
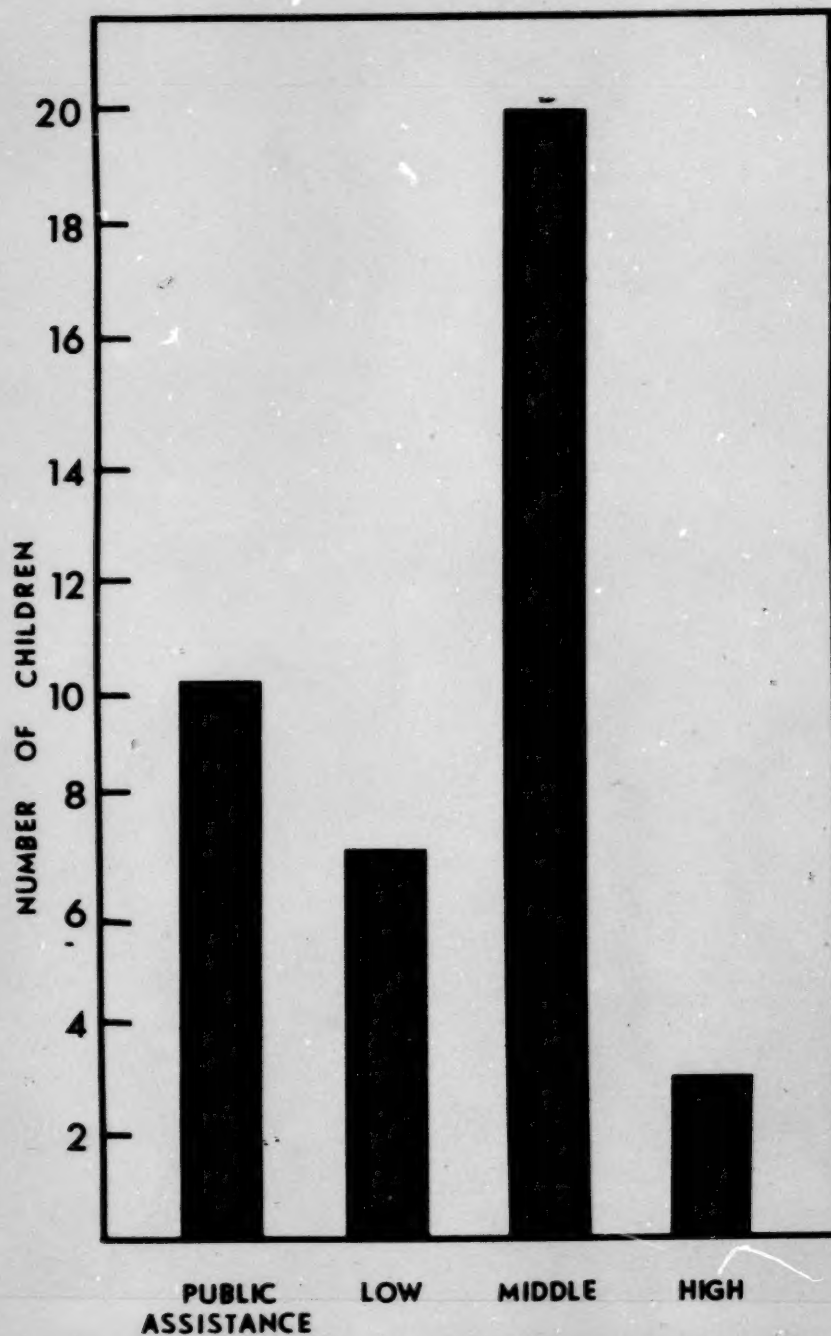


FIGURE 2

SOCIO-ECONOMIC STATUS

N = 40



ETHNICITY

N=40

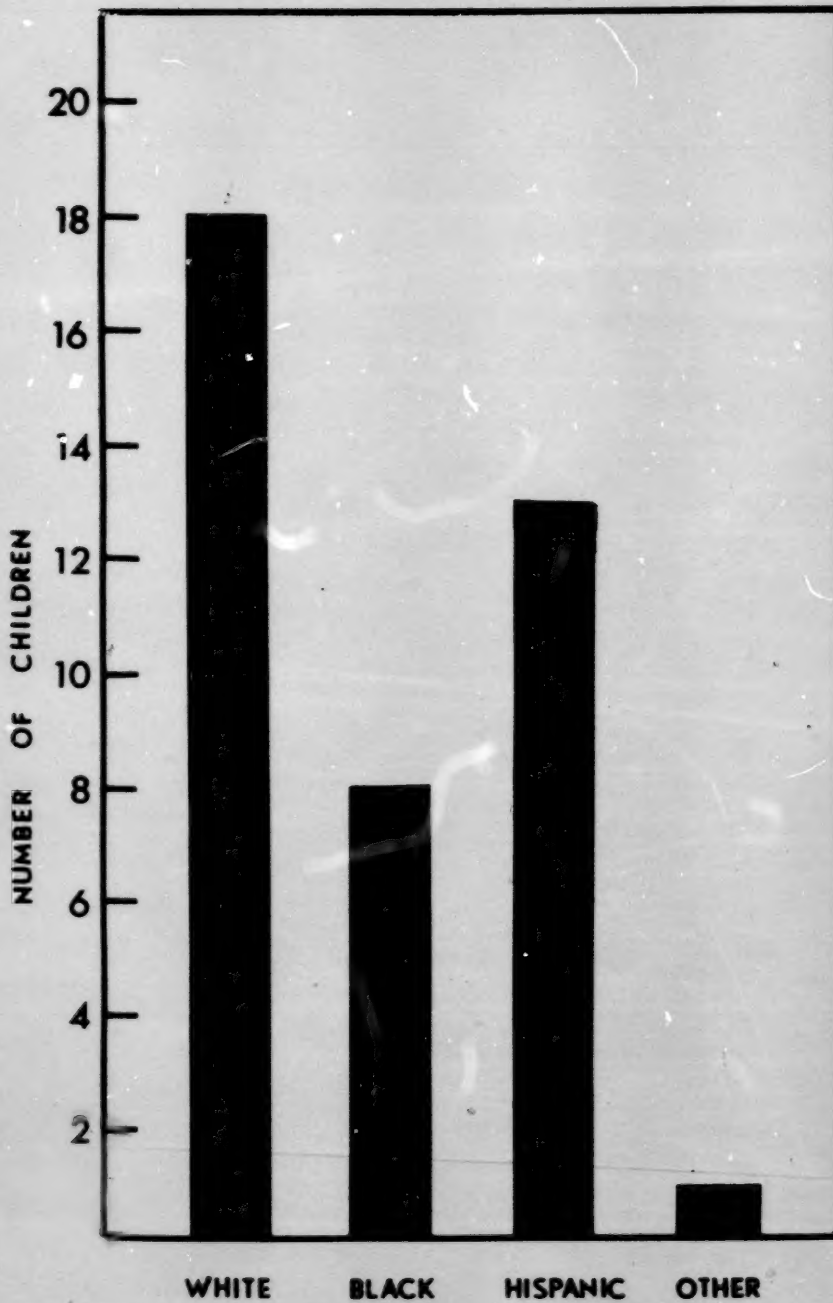
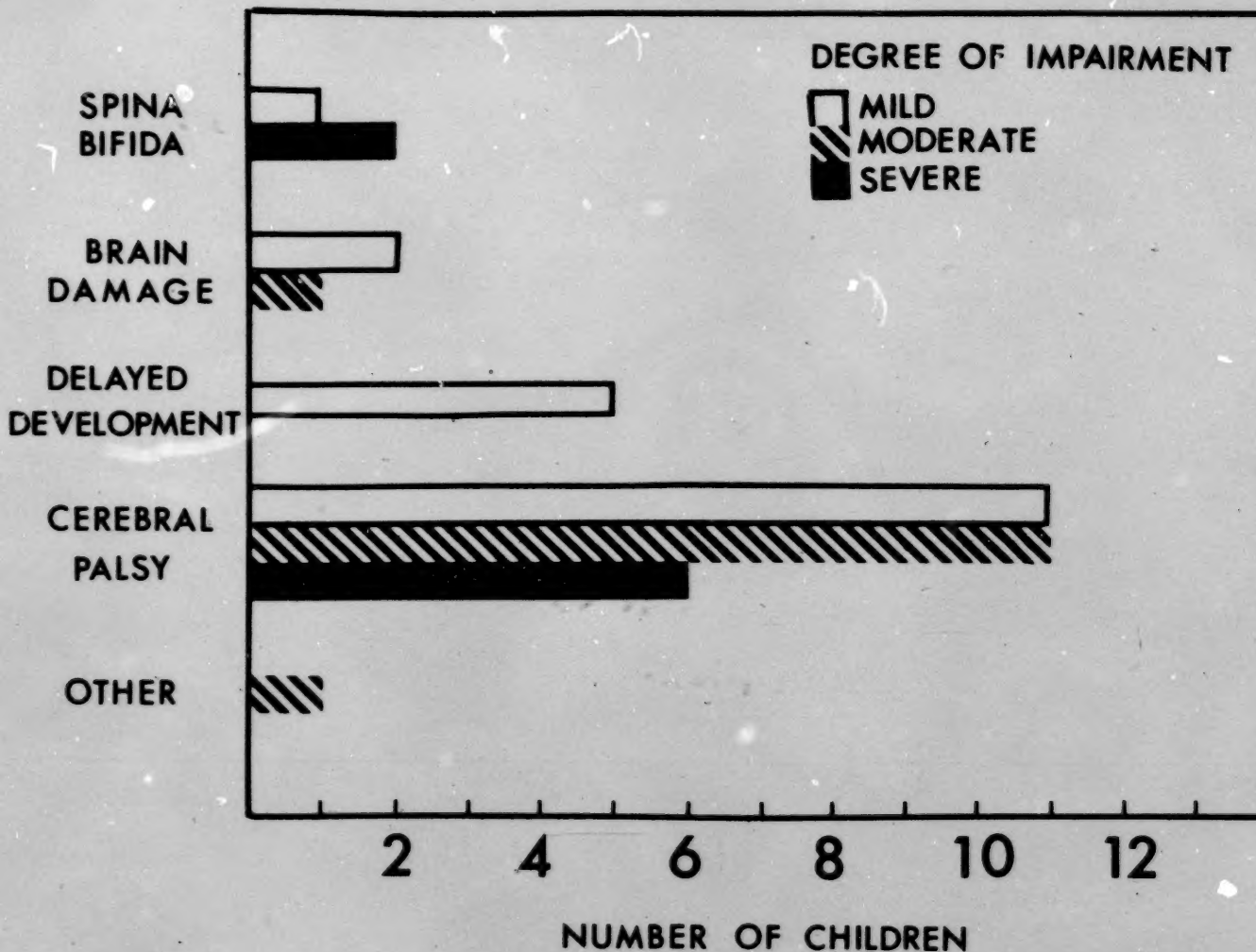


FIGURE 4

MEDICAL DIAGNOSIS AND DEGREE OF IMPAIRMENT OF MOTOR FUNCTION

N=40



Joint Clinical Judgments -- Sum Delay Scores

Examination of medical information alone does not identify comparable levels of functioning. When the concern is for accurate information from which teachers can begin to develop individualized educational programs, medical descriptors offer only minimal data upon which to base judgments and goals. The infant education program is concerned with more than the functioning of the child in terms of physical status and motor abilities. It is concerned with relationship thinking, work with educational materials, affect, social skills, language development, and independence.

Since medical diagnoses do not adequately describe the individual child, nor do MA scores or language scores give a full description, we have developed a delay score (a composite of clinical impressions) to help to describe the severity of a child's developmental delay. Each discipline assesses the severity of delay (e.g., psychology, intellectual delay; physical therapy, motor delay; speech pathology, language delay) on the basis of the child's functioning during the first few weeks on program. (As with MA scores, the lower the score, the more severe the delay, with 1 = severe delay, 2 = moderate delay, 3 = mild delay, and 4 = normal development.) The educational staff rates the child in each comparable area (motor, language, intellectual, social, and affective development). These are then compared with the therapists' judgment. Where discrepancy exists a joint decision is reached. For each child there is a delay score in each of five areas as well as a sum delay score. The combination of delay scores and medical diagnosis gives an individualized developmental picture of each child, which can aid in planning an educational program. (See Table 3, Appendix IV for medical diagnosis and joint clinical judgment as to degree of disability and delay upon admission.)

Procedure

Sources of Data

Logs. The primary source of data used in this study was the log written by the child's teacher. Each log is a prose record containing the teacher's intent for each activity, a description of the materials and/or individual involved (if it is a social activity), the child's responses, and other salient information regarding the child's behavior during a session. (See Item 1, Appendix IV for sample log.) This method of data collection was originally selected as a source of information for the educators in their initial desire to "track" the child. After a series of conferences among the educators and the research staff, the use of these logs was determined to be in harmony with an educational philosophy of concern for the process of change and the dynamic interaction of differential aspects of development. It was felt that sequentially ordered checklists (Caldwell, 1967) and composite profiles (Sanford, 1971; Wood, 1974) did not permit the description of evolving competencies and the variations of experiences and materials presented in educating this diversified population.

To obtain a complete description of the status of the child over time it is necessary to have a continuous record of functioning throughout the child's time on program. Therefore, logs were written on approximately three mornings per week for the duration of each child's stay, yielding an average of 36 logs for each child (N of logs = 1,500).

Videotapes. A second source of data was the videotaped evaluation sessions. A tape was made during the first 2 weeks and again during the last 2 weeks of the child's time in the Infant Program. These videotapes were similar in nature to the screening tape (see p. 7) but differed slightly since the session was conducted by the child's teacher after a relationship with the child had been established. By this time additional information had been accumulated related to the child's level of functioning. Thus, materials were more carefully preselected. As before, the tasks were modified based upon the child's initial responses. The teacher replicated the materials and tasks of the pre tape during the pre-discharge session adding new activities or equivalent tasks to assess emergent abilities. The nature of these taped sessions can be partially compared to the psychologist's testing session. However, there is a flexibility in time and mode of presentation and modification or substitution of tasks which permits the teacher to explore and determine the child's optimal level of functioning in a non-standardized format.

The Evolution of the System of Analysis*

The use of logs as a data base presented a critical initial problem. A system had to be developed to code and then to quantify the prose data.

The educational philosophy was reflected in programmatic areas related to the child's development. Each area was identified as a parameter or dimension for examination and study. General dimensions delineated were those considered to be salient in the growth and development of young children -- handicapped as well as normal. A series of meetings between the research team and the education staff led to the establishment of categories (dimensions) of behaviors. The following are samples of the dimensions. Each sample was selected from the teacher's logs reporting learning experiences offered to different children on program.

1. Interaction with Materials --

"I put G in a quiet corner and gave him the unit blocks and a small car. I demonstrated how to build a ramp. On his own initiative (he has done this before) G picked up the car and rolled it down the ramp. He repeated this again, looking at me intermittently and smiling. I used other blocks to build a bridge. G knocked it down and built his own bridge (a duplicate of mine). He constructed it in such a way that when the car rolled down the ramp, it rolled through the bridge. Looked up at me and applauded."

* Two research teams have contributed to the development of this system. Dr. Lillian Shapiro and Mrs. Carol Neiditch were instrumental in the early formulation of the system and coding of logs on the first 20 children. Subsequent refinements and coding were the work of Mr. David Gitler, Miss Barbara Schwartz, and Miss Ora Ezrachi.

2. Environmental Awareness --

"I put the plant we had planted yesterday on her lap and told her we were going to water it. She followed me into the bathroom. I gave her a cup. She poured independently. She kept looking at the bottom (of planter) to see if the water was coming out. I had emphasized the day before, when we planted the shoot, that when the water came out of the bottom, we stop watering."

3. Social Responsiveness --

"He smiled at me from his crib. I took him out and held him near Z's crib. He stuck his hand into her crib (she was in there) in Z's direction. When she reached for it, he quickly pulled it out. He played this teasing game with her for a while."

4. Expressive Communication --

a. Verbal Communication:

"He looked at the milk on R's lapboard and said, 'Juice?' I said, 'No, today we're having milk.' I then repeated 'milk' as I set up the table for snack. He said, 'Milk' when he was given his cup."

b. Gestural Communication:

"She put down the brush she had been using to put paste on the paper. I asked if she were done. She nodded 'yes'. I asked where she wanted me to put the paper she had finished. She pointed to the wall near the counter. I taped it up. She nodded 'yes' in agreement."

5. Affect --

"As A's mother closed his suitcase, I said, 'See, you are going home.' A's father picked him up and carried him to the elevator. His physical therapist came up to him. He hit out at her crying and angrily screaming, 'No! Go away!' We had told him he was leaving and here he was being betrayed. His reaction was strong and appropriate."

6. Gross Motor --

"I hung the crib activator between two cribs. She moved toward it, then stopped. I coaxed her to get moving until she finally reached the activator. She reached and pulled on the center beads. Felt around the bar, pulled on it in an attempt to see if it were rigid enough to pull up on (my interpretation). She did pull to a kneel stand, but was unable to pull to standing independently. I helped her. She seemed unsteady holding on by one arm. Soon lowered herself to the floor."

7. Fine Motor --

"After snack I gave her some crayons. She carefully tore the paper off of each of the three crayons before scribbling on the paper."

8. Assertiveness, Independence --

"The spina bifida cart was sitting in the bathroom. She looked at it, hitched (on buttocks) over to it, and with great, concentrated effort, began to move it. Seemed to be trying to get it out of the bathroom but was having a lot of trouble. I tried to help. She responded to my help with loud vocal protests."

Within each category gradients of differences among behaviors were further defined to describe better the functioning of this specific multi-handicapped population. Seven dimensions evolved and have been refined. (See Appendix II for complete coding guidelines, definitions, and examples.) In four dimensions these differentiated levels of functioning were hierarchically ordered following established patterns of complexity related to existing norms.

Hierarchical scaling was developed for the following dimensions of functioning: Interaction with Materials (M), Awareness of the Environment (En), Social Responsiveness (So), and Expressive Communication (Co). At the lowest level of each of these dimensions a passive level was established to indicate that a response was expected (based upon the child's prior performance or established ability), though none was evident. The remaining levels within each dimension were scaled to reflect increasing complexity.

The on-going refinement of the coding system has resulted in substantial changes in three dimensions. Within the hierarchical dimension of Interaction with Materials, one of the coding categories, the M5 level, refers to the use of materials according to task demands as structured by the teacher or as implicitly designed into the material. (This denotation can be applied both to a child splashing in water and to a child successfully completing a complex shape discrimination puzzle, although the age levels at which a child could complete each of these tasks would differ.) It was decided, therefore, to focus specifically on that level of the hierarchy (related to the demands of a task) and the age at which a competency is expected to emerge. A ceiling age would be assigned to each task on this level (excluding those which were imitative) and would yield a ceiling age level for the child's appropriate interaction with materials at M5. This refinement is discussed in Appendix I.

Within the dimension of Expressive Communication, parallel hierarchies were established for gestural and verbal communication. This distinction was felt to be of particular importance in examining the language of multi-handicapped children whose physiological and neurological problems often impede verbal production. Age levels were then assigned to verbal expressive communication. This is illustrated in Figure 1, Appendix I.

One dimension, Sensory Responsiveness, was employed in the coding of the first 20 children in the study (Children A - T). This dimension is presently incorporated within the En dimension. The Awareness of Environment dimension was also refined and expanded to include relationship thinking. This refinement is illustrated in Figure 2, Appendix I.

The Affect dimension (Af) has three components: type (neutral, positive, or negative); quality (appropriate or inappropriate); and intensity (passive, mild or moderate, and extreme).

The remaining two categories, Gross Motor Activity (MO) and Fine Motor Activity (mo) were not scaled hierarchically. The great variation in motoric disorders in our population precludes the valid use of specific potential levels of attainment. Thus, codings in this dimension differentiate only between the presence or absence of motor activity in situations where it would be expected (on the basis of the child's physical and/or organic limitations).

In addition to the presence or absence of a given behavior, consideration was given to the independence and initiative exhibited by a child. This seems of particular importance when one is aware of the inordinate amount of persistence needed by multiply handicapped children in order to achieve desired goals. Within an educational environment engineered to foster independent exploration, concentration and focus are on the examination of the extent to which a child initiate interactions with materials, people, and the environment. As a result, two types of independent behaviors were delineated -- those in which the child commenced an interaction, a self-initiated behavior (in), and those in which the child was assertive during an interaction (AS). (Appendix II presents definitions for qualifying behaviors.) Assertiveness itself could manifest itself in a variety of forms, such as: simple assertion (as), persistence, especially when physical impairment made the end goal difficult to achieve (pas), a clearly indicated preference (pras), a desire to terminate a task or interaction before the teacher thinks that it is concluded (tas), or a strong negative reaction or rejection of someone or something (nas). These independent codings were established as modifiers of behaviors in all categories where they were applicable. (Affect is not modified by these independent codings.)

There are behaviors which appear to be symptomatic for a specific child. These idiosyncratic behaviors usually become evident during the first few weeks. (They may include such behaviors as head-banging or fear of loud noises.) Since they are symptomatic, they are not considered as falling within any given dimension. They are individually noted and tallied regardless of the activity during which they appear.

Despite the specificity permitted by the dimensions and modifiers, there are still log-reported instances in which a particularly rich incident might be lost if not separately annotated. Therefore, even after devising a system to examine quantitatively dimension-related behaviors, there is still concern with the qualitative differences which describe even more precisely the uniqueness of each child. These incidents are annotated.

Reliability of Coders

When dealing with such a divergent population, a degree of consistency in coding from one child to the next must be maintained. To do this it was necessary to establish an intercoder reliability and consensus for each child. Coding, therefore, necessitated a thorough prior knowledge of the individual child -- not distance from the child. In addition, it was necessary to have coders with sufficient background in child development to distinguish subtle differences in functioning. Qualitative differences within the prescribed guidelines for a dimension vary slightly, depending upon the nature of the child's disabilities; in other words, the coding system is adaptable.

A consensus process was established. Each of two coders coded a set of six logs, two randomly selected from each third of the child's stay on program. Differences between coding judgments were then discussed, and a joint decision was reached. The degree of reliability was determined on a child-by-child basis. In calculating reliability coders had to match both on the dimension and on the level within each dimension, quite a stringent requirement if one considers that each of the hierarchical dimensions has several levels. Reliability data (Wright, 1967) are presented separately for both coding teams, individually and jointly (Tables 4a - 4c, Appendix IV).

Steps in Analysis

Log Data. For the purposes of this study, logs were coded following the child's discharge. After reliability and consensus were reached (all discrepancies resolved between the coders for the six reliability logs), the remaining logs were divided in half, and two members of the team coded each child's records. Coding proceeded in the order of randomly assigned numbers. This guaranteed that the coders could not be influenced by knowledge of the duration of time in the program as a possible determinant of level of functioning. During the coding process the coders relied on their previous judgments and discussed any behavior which was particularly difficult to code.

Since each log contained descriptions of a number of different developmental activities, it was decided that behavior should be analyzed on the basis of internally coherent episodes. An episode was defined as a sequence of behaviors related to a specific material (e.g., I gave her a doll and a hat), an activity (snack time), or social interaction (e.g., the child's response to the teacher when she entered the room). Within the framework of the Infant Program, a child's behavior is seen as an interwoven pattern, i.e., a child's response to a material might also contain a response to the individual presenting the material. Therefore, each episode may contain codings in one dimension or several clusters of coding. (Appendix II contains detailed coding guidelines. See Item 2, Appendix IV, for sample coded log.)

Following the completion of these procedures, the codings from each log were noted on a transfer sheet. A single line contained an abbreviated description of the activity, the codings related to it, and any annotations. Thus, a completed transfer sheet provided a visual summary of the numbers of codings by dimension and the frequency of coding within a given dimension.

Videotape Data. Videotaped pre and post sessions were also found to be amenable to the same coding system with several limitations. The videotaped sessions were usually recorded while the child was seated at a table, thus limiting evidence of gross motor skills. The TV camera is mounted in the ceiling (see Figure 1, Appendix III). Therefore, from the angle at which recordings were made, it was difficult at times to see the child's facial expression, and affect could not always be accurately perceived. In addition, the limited time and nature of these sessions also made it more difficult to assess accurately the existence of fine motor skills. The coding process involved both members of the research team first viewing the tapes and then arriving at a joint decision for coding. One individual did the actual coding directly on annotated descriptive transfer sheets. These transfer sheets contained descriptions of each activity, a coding for the response to the material (M), and all perceivable interactions with the environment (En), interactions with individuals (So), and use of expressive communication (Co).

Tallying of Logs

Logs were refiled chronologically after completion of coding and transferring. Actual tallying of data was done from the transfer sheets. For purposes of establishing a common data base, each child's stay in the program was divided into time periods. Each time period included approximately six logs, which usually corresponded to 2 weeks of the child's program. If the child had been off program (i.e., the child was ill or was having tests), then the time period might have covered a longer length of time. The majority of children have logs covering six time periods (N = approximately 36 logs per child).

For every dimension each type of independent behavior (IND) and all levels of functioning were tallied separately per time period. These absolute frequencies were then recorded on data transfer sheets (Item 3, Appendix IV). The percentage of the child's behavior was next computed per level of each dimension and for all the various independent behaviors within each dimension. To equate behaviors for all children the average or mean number of behaviors was calculated for each level of a dimension per episode of behavior. Variability in length of logs or number of logs was thus eliminated.

The levels within the hierarchical dimensions (M, En, So, Co) were next weighted to reflect and greater separate the qualitative differences (see sample tally sheets, Item 4, Appendix IV, for examples). Each mean was multiplied by a designated weighting. Passive behaviors (level 1) were given a weighting of zero (0); level 2 was given a weighting of (1), etc. For the Communications dimension there were parallel weightings for gestural and verbal coding; the levels of AW and W were both weighted by 3. The sum of all absolute, weighted, and weighted mean scores was then used in compiling a summary total sheet for all dimensions (Item 5, Appendix IV). The data on these summary sheets were then key-punched for use in data analysis.

Testing the Validity of the System and of Its Refinements

As one early check on the empirically derived data generated by the total observation and analysis system, rankings of the first 20 children in the study were compared to a ranking done by the master teacher. This comparison was for level of functioning in each of the four hierarchical dimensions. Rank-order correlations were obtained and were found to be significant in all areas except for past ranks in the Awareness of Environment dimension. (Tables 5 and 6, Appendix IV, present these findings.) Therefore, it appeared that the system was extracting data which were clinically meaningful. (In the case of the En dimension the finding of inconsistencies led to the refinement of the dimension.) A more severe check of validity was later instituted.

Although the original impetus for the systematic study of children emerged from observation (i.e., the "baby biography"), there is relatively little contemporary use of systematic observation in American developmental psychology (Brandt, 1972; Caldwell, 1967; Hutt & Hutt, 1970). This is true for the study of both normal and deviant populations. Despite the extensive and important work of Barker and his associates (1963), who have emphasized the observation of naturally occurring events within an environmental context, the observational method continues to be viewed by the majority of psychologists as overly biased and as imprecise. Experimentalists have felt that the "natural setting" contains too many uncontrolled sources of variation. At the same time, however, many educators have stressed the importance of a teacher's observations as a potentially rich source of data (Cohen & Stern, 1958; Rowen, 1973). The use of records produced by a participant observer has been particularly criticized. It has been felt that investment and participation in an activity introduces too great a degree of subjectivity.

Testing the Validity of Employing Teachers' Logs: A Substudy

To assess the validity of employing teachers' logs as the primary source of data, a substudy directly compared four alternative data sources (master teacher, intern teacher, nonparticipant observer, and videotape recordings).

Method for Substudy

Subject. The child selected for observation (Child BB) was medically diagnosed as "congenital cerebral palsy, spastic diplegia type." On admission to the program she was 29 months of age and had an MA of approximately 12 months, determined from sections of the Bayley Scales.

Methods of Observation. The data for this study were collected during the course of six full morning classroom sessions (9:30 a.m. - 11:30 a.m.) over a 2-week period. Four methods of observation were used. They were:

1. Participant observation by the master teacher (MT), who worked directly with the child and subsequently wrote log records (logs) which included descriptions of educational materials and activities presented to the child and the child's behaviors in response to these situations. These records also contained descriptions of the teacher's intent in presenting a given task.

The master teacher had over 10 years of experience in early childhood education before coming to the Infant Program 5 years ago. Over the course of the last 3 years, she had been responsible for writing the log records on at least two children on program per week. In addition, she had supervised intern teachers in their writing of many log records. She had also been involved in the development of the coding system;

2. Participant observation by an intern teacher (IT), who assisted the master teacher and also worked with other children in the room. Concurrent daily log records were also written by the intern teacher.

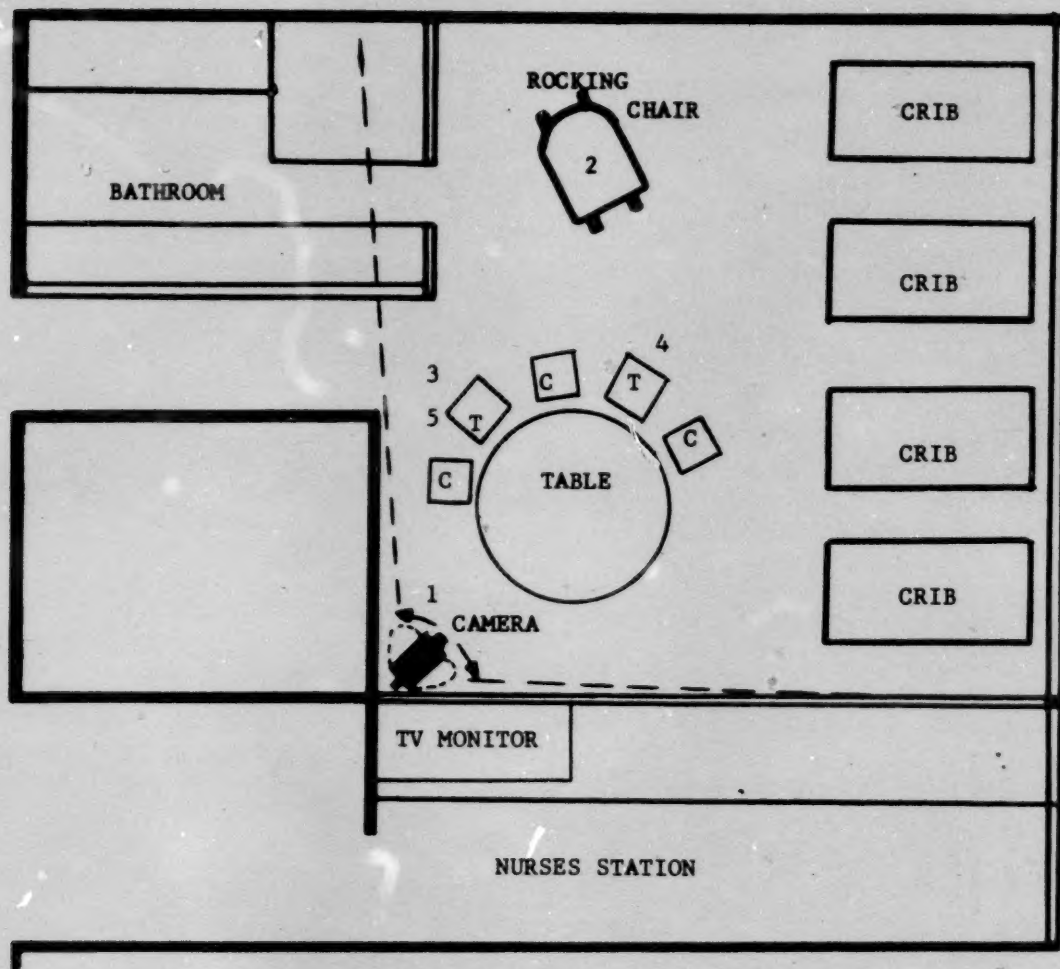
The intern teacher had approximately 2 years' experience in student teaching placements prior to her internship with the Infant Program. Once her placement began, she was familiarized with the coding system and wrote her log records under the supervision of the educational staff and the research staff. This practicum training commenced several weeks prior to the inception of this study;

3. Non-participant observation (NPO) by an observer seated in the room. This observer wrote detailed running records during the course of each reported morning session in an attempt to describe objectively all actions of the teacher, materials, and situations presented to the child, as well as the child's responses.

The non-participant observer had several years' experience in early childhood education both in a teaching capacity and as an observer of classroom behavior. Prior to the inception of the present study, she observed and wrote several pilot observational records;

4. Videotape recordings (VT) of the session, with recording begun as the teachers entered the room. The videotape recordings were made with a Concord VTR 700, monitored and controlled from an adjoining room by members of the research team. From the position on the ceiling the camera could be panned from left to right and tilted up and down. A zoom lens permitted the camera to "zero in" on an activity at the far end of the room. Two microphones, located in the ceiling, picked up all sounds in the room (see Figure 5, p. 23).

Figure 5. Diagram of room used in Validity sub study



Key:

1. Videotape monitor
2. Nonparticipant observer
3. Master teacher
4. Intern
5. Child BB

Procedures for Observing and Recording by Study Personnel. At the end of each morning session the master teacher wrote a set of detailed notes. Within a few days these notes were transformed into a log, which has a prose format. The intern teacher followed the same procedure outlined for the master teacher. The observer maintained on-going running records. She remained fairly stationary throughout the sessions, moving only if observation of the child was hindered by some obstacle. From this vantage point of from four to eight feet, all observed behavior was recorded.

Procedures for Analyzing Data. Each behavioral record and taped sequence were first divided into behavioral episodes, each episode focusing on a specific activity or interaction (Wright, 1967). For comparison purposes all data from all four sources were then coded with the same system. Videotapes were reviewed by members of the research team and were coded directly onto transfer sheets, which were heavily annotated with descriptions of the activity, language used, etc. All other records were coded directly by members of the research team, with codings and annotations then being transferred to an identical transfer sheet.

Upon completion of coding all data were tallied, and percentages and means/episodes were derived. Means obtained in the hierarchical dimensions (M, En, So, Co) were then weighted to differentiate further levels of behavior. Results were then compared across all four data bases. One preliminary finding was expected. Not all episodes were to be found across all four data sources. This was anticipated because of limitations in each source of data. Every log record depended on memory; the non-participant observer's records depended on her ability to record everything that occurred; the videotape recordings depended on the mechanical and electronic adequacy of the system. (In the case of the videotape, for example, some episodes were missing because the tape was being rewound. In other instances the pan/tilt mechanism malfunctioned and thus did not allow for the recording of a behavior. In addition, as Figure 5 indicates, from the vantage point of the camera it was not possible to see all activities conducted at the sink area or at the bath tub.)

Twenty-one identical episodes were found across all four data sources. The codings contained within these matched episodes formed the basis for comparison and analysis.

Results of Substudy

Comparison of data from the four sources began with a measure of "density of coding," which was defined as the number of behaviors found to be in codeable form in each source. Density was calculated as the sum total of behaviors coded per dimension per data source. Findings are presented in Table 1, which follows.

Table 1

Validity Study:

Density of Codeable Material per Observer
Based on Matched Episodes

<u>Dimension</u>	<u>Teacher</u>		<u>Intern</u>		<u>Observer</u>		<u>Videotape</u>	
	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>	<u>No.</u>	<u>%</u>
M	51	26	54	32	71	26	58	26
En	28	14	18	11	24	9	28	13
So	25	13	16	9	41	15	37	17
Co	17	9	7	4	29	11	16	7
Af	11	5	11	7	18	7	17	7
MO	65	33	62	37	85	32	67	30
mo	0	0	0	0	0	0	0	0
Total	197		162		268		223	

Generally, the non-participant observer produced records which allowed the greatest number of codings. That is, these records contained the highest frequency of codeable material. Each episode furnished a clear and explicit behavioral description and, therefore, required little inference on the part of the coders. The videotape recordings, because they could be reviewed when indicated (in case of ambiguity or lack of clarity) yielded the next highest level of density. The master teacher's records and intern teacher's were third and fourth, respectively. This was to be expected given the master teacher's dependence on memory and the intern's involvement with the other children in the room.

A profile of data on the child from each source was then obtained for each of the 6 days and for the total 2-week period. A total of 20 of the 36 correlations among observers of matched episodes based on percent or proportion of dimension was significant at the $p .05$ level or better. This indicates that those episodes, which were reported by all sources, yielded similar qualitative information (see Tables 2a and 2b, which follow).

Table 2a

Rank Order Correlations on All Dimensions
Between Observers Based on Percentages

	<u>Day 1</u>	<u>Day 2</u>	<u>Day 3</u>	<u>Day 4</u>	<u>Day 5</u>	<u>Day 6</u>
Videotape - Observer	.971*	.900*	.671	.886*	.543	.886*
Videotape - Teacher	.843*	.886*	.843**	.314	.457	.843*
Videotape - Intern	.900*	.586	.700	.671	.729	.914*
Observer - Teacher	.829*	.957**	.729	.429	.943**	.943**
Observer - Intern	.900*	.614	.129	.771	.857*	1.000**
Teacher - Intern	.986**	.729	.529	.729	.857*	.934**

Table 2b

Rank Order Correlations on all Dimensions
Between Observers Based on Weighted Means

	<u>Day 1</u>	<u>Day 2</u>	<u>Day 3</u>	<u>Day 4</u>	<u>Day 5</u>	<u>Day 6</u>
Videotape - Observer	.671	.714	.329	.914*	.143	.657
Videotape - Teacher	.464	.886*	.828*	.700	.129	.629
Videotape - Intern	.943**	.571	.471	.585	.643	.929*
Observer - Teacher	.871*	.943**	.529	.886*	.985**	.986**
Observer - Intern	.757	.486	.286	.843*	.814	.814
Teacher - Intern	.557	.543	.814	.943	.829	.771

* p < .05

**p < .01

Discussion and Implications of Substudy

These findings suggest that the logs which the master teacher wrote did, in fact, accurately report the child's performance. Even though all of the activities of the day were not recorded, those activities or behaviors which were selected were truly representative of the child's functioning. Furthermore, the coding system appears to be strong enough to delineate information from all sources used.

This substudy also produced additional information on the benefits of each source of data, the desirability of using a particular source for analysis of a specific type of information, and confidence in the coding system itself.

The extent of experience and professional competence of the teacher, intern, and observer was a contributing factor in the content and quality of the material available for coding. The experience and competence of the coders in the application of a sensitive coding system were also factors in generating the results of this study. Furthermore, each method of recording appears to have a pattern of strengths and weaknesses.

Data from Master Teacher. The teacher's logs did not contain the same quantity of information as the other sources. However, they did generate sufficient quantitative information in the areas of interaction with materials, degree of awareness of the environment, extent of social responsiveness, and amount of motor activity. This record also contained the teacher's intent in various situations, which added to accuracy in coding of the child's behavior. These teacher's records did not yield the same quantitative information with reference to language or affect as the other sources, e.g., the number of times a child babbled, gestured, laughed, or cried. The presence of this behavior was noted with a loss of quantity but with accuracy in quality.

Data from Intern. The intern's logs, although lengthier than the teacher's, did not contain as much codeable information. In the areas of the child's work with materials and motor ability, there was information quite similar to that derived from the teacher's. Since the intern was not always working with or in the proximity of the child at the same time as the master teacher, there was not as much information about language, affect, social responsiveness, and environmental awareness.

Data from Non-participant Observer. These anecdotal records produced the greatest amount of codeable information. These recordings were not based on memory and were not affected by extraneous noises. This method produced the most detailed record of the child's babbling and expressive language. It also produced a detailed record of the child's manner of working with materials and the amount of movement the child engages in during each session. Since the observer was required constantly to write, the child's nonverbal activities, such as eye contact and gesture, were less likely to be consistently recorded.

Data from Videotape. The videotape was a permanent record of all activity in the room. It could be replayed and did not depend on memory or subjective impression. With the type of equipment used for this study, it was not possible to record accurately all of the child's language. This was reflected in the proportionately lower quantity of codeable material in this category. (See Density of Coding, Table 1, p. 25). The use of this method of recording a child's growth did have several limitations. The equipment involved a substantial initial investment*, constant purchase of videotapes, and an occasional problem of malfunctioning equipment. In addition, it was not selective in what it recorded and, therefore, resulted in lengthy sections which were not codeable.

Conclusions from Substudy

1. Although there is variability among these four data collection systems, the correlations on episodes recorded in all four systems reflect an extremely high degree of congruence in the material generated by each. The master teacher's records provide more than sufficient data for rigorous analysis.
2. Prior to choosing any one of the data collection systems, it is advisable to determine which area of the child's functioning is of greatest interest, since each of the various methods have strengths in different dimensions or groups of dimensions.
3. The experiential backgrounds of the various observers is a contributing factor in the accuracy of the material that is recorded; therefore, varying staff competencies should influence which method is selected for use in different settings.
4. All four methods generate sufficiently detailed information to be analyzed with the present coding system in assessing change as a result of the impact of an educational program.

*Available for this research project by prior architectural design and other funding sources.

Application of Age Level Analysis to Interaction with Materials Dimension

The refinement of the Interaction with Materials dimension (see Appendix I) was extended to all M5 level codings for all log data and for all videotape data, yielding more than 600 activities and tasks classified for age levels. Congruence among pre log mean ages and pre videotape ages and among post log mean ages and post videotape ages was high (pre: $r = .80$, $p < .01$; post: $r = .90$, $p < .01$). Table 1, Appendix I, presents ceiling age levels in months for log data across all time periods for all 40 children in the study. This table also presents ceiling age levels in months for pre and post videotapes.

Application of Age-Level Analysis to Communications Dimension

New gestural and vocal codings were applied to logs of all 40 children in the study (see Appendix I for discussion). Figure 1, Appendix I, presents weighted mean scores divided into gestural and vocal contribution. An individualized analysis of qualitative and quantitative features of each child's verbal communications was conducted. Data used to arrive at the age level included: (a) coding level, (b) size of vocabulary, (c) syntax and length of sentences, (d) presence of questioning negatively, (e) presence of pronouns, adjectives, adverbs, and prepositions. When analyzing the age levels derived from the log records versus those obtained through a formal speech pathology evaluation for children U - DD, a high positive correlation was obtained (pre measures: $r = .98$, $p < .001$; post measures: $r = .85$, $p < .01$). These results indicate that this is a valid method for studying a child's verbal expressive communication.

Application of Refined Environment Dimension

It was particularly important to develop greater precision in the operational definitions of this category because our program is based on the thesis that exploration of and interaction with the environment are essential components in the development of the young child -- handicapped as well as normal. Appendix I contains a discussion of this refinement. New and more graded levels reflected an increased refinement, resulting in a more accurate picture of the response level of each child in this dimension. The new coding system has been applied to succeeding data. Another indication of the greater clarity provided by using six levels rather than three was that there was the finding of greater intercoder reliability on this dimension than previously found. Figure 2, Appendix I, presents results of this application.

RESULTS

The findings presented in this section incorporate the refinements discussed on pp. 17 and 18 and which are described in detail in Appendix I. In order to facilitate the presentation of findings, this section will be organized as follows: Results obtained from the study of the total sample ($N = 40$) will be divided into (1) those findings which relate to the strengths of the coding and analysis system and (2) those findings which relate to the study of functioning and changes in functioning in the 40 children who comprise our sample. Findings on subgroups of children will also be presented first in terms of the system and then in terms of change. This will include representative data on individual children. These findings will precede the presentation of data on an individual child. A narrative case history is included. Narrative case histories on additional children are presented in Appendix VI.

Results for N of 40

System Findings -- Dimensions

Log Data. Pre and post scores in each of the seven psychoeducational dimensions were correlated. (For the hierarchical dimensions weighted means were employed, but means were employed for the three non-hierarchical dimensions). All correlations were found to be significant, indicating an internal consistency within the dimensions being studied. These results are presented in Table 3 below.

Table 3

Pre-Post Correlations within Dimensions: Log Data ($N = 40$)

Dimension	<u>Hierarchical</u>				<u>Non-Hierarchical</u>		
	M	En	So	Co	Af	MO	mo
Correlation	.65**	.73**	.64**	.92**	.40**	.59**	.59**

** $p < .01$

The four hierarchical dimensions were then separately intercorrelated. A similar pattern of internal consistency emerged for both pre and post periods. Table 4 presents these results.

Table 4

Log Data: Intercorrelation of Hierarchical Dimensions
Pre and Post (Weighted Means) (N = 40)

	<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>	<u>Total</u>
<u>M:</u>					
Pre	-	.45**	.47**	.60**	.79**
Post	-	.44*	.54**	-	.67**
<u>En:</u>					
Pre		-	.33*	-	.57**
<u>So:</u>					
Pre			-	.51**	.77**
Post			-	.50**	.81**
<u>Co:</u>					
Pre				-	.60**
Post				-	.81**

* $p < .05$

** $p < .01$

Videotape Data (N = 39). The findings obtained from analysis of the teacher's written logs were supported by data obtained from the analysis of pre and post videotapes (see p. 15 for explanation). Pre and post scores in the four hierarchical dimensions were found to be significantly correlated from pre to post (M: $r = .62$, $p < .01$; En: $r = .39$, $p < .05$; So: $r = .49$, $p < .01$; Co: $r = .59$, $p < .01$).

Intercorrelation of the hierarchical dimension scores obtained from pre and post videotaped sessions with educational materials were also found to be consistent with the findings obtained from the log data. (Table 1, Appendix V, presents these results.)

Results from analysis of both log and videotape data indicate that, when the total sample is examined, (a) a child's relative level of functioning and position in the group remains relatively stable from pre to post as a result of concurrent change in the entire sample, and (b) a child who is functioning at one level in one hierarchical dimension is likely to function at a similar level in the other hierarchical dimensions.

This is consistent with our long clinical experience. Although our population of children appears to benefit from an individualized program, a severely damaged child can only be assisted within the zone of his organic and intellectual limitations. Concurrently, we would expect a mildly impaired child to improve to varying degrees from a status of minimal deficit to an approximation of normalcy.

This is a further indication of the strengths of the system; it is able consistently to measure functioning (both pre and post) within, as well as across, dimensions. These findings are further strengthened if one considers that any given dimension encompasses a wide range of behavior and graded levels of functioning. The system is, therefore, sensitive throughout the entire range of behaviors and levels of functioning.

Relationships among Dimensions. Further examination of the pattern of intercorrelations among the hierarchical dimensions for log data showed that the M, So, and Co dimensions were highly intercorrelated. That is, a child's level of functioning in one of these dimensions was related to his level of functioning in the other two dimensions. The strength of this interdependence was studied by serially partialling out the variance of one variable from that of the other two variables.

Social Responsiveness and Communication were found to be significantly correlated even when the variance of Interaction with Materials was eliminated. That is, these two dimensions were found to be more highly related to each other than either of them was to Interaction with Materials dimension. This relationship was found for both pre-to-pre and post-to-post comparisons. (Results are presented in Table 2, Appendix V.)

In order to determine the degree to which MA contributed to the intercorrelations among So, Co, and M, the effect of MA was partialled out. Results are presented in Table 2, Appendix V. It was found that MA did affect the strength of the correlations between Interaction with Materials and Social Responsiveness, between Interaction with Materials and Communication, and between Social Responsiveness and Communication. In all cases the previously significant intercorrelations were lowered or were rendered non-significant. This suggests that the original correlation was dependent in each case upon the association between each of the dimensions and MA. In other words, a child's MA was predictive of his functioning in these dimensions.

In order to test whether these relationships (MA-M, So-Co) were related to CA, the effect of CA was partialled out from their intercorrelations. The strength of these relationships did not change significantly, indicating that for our population CA was not related to functioning in these dimensions. Table 2, Appendix V, presents these results.

Thus, two factors, both related to MA but independent of each other, emerged. The first was an Interaction with Materials-MA factor. The second factor consisted of Social Responsiveness-Expressive Communications and MA. The So-Co relationship was not affected by M. The Interaction with Materials dimension subsumes handling, manipulation, and problem-solving. All of these activities are partially tested and scaled in formal psychometrics. Therefore, the correlation between MA and the M dimension is not unexpected. The Social Responsiveness-Expressive Communication-MA relationship suggests an association of social interaction with expressive ability and the exchange of ideas and feelings, and reasoning. These abilities are also examined in formal testing.

It appears that CA does not contribute to these relationships and, therefore, is not a valid means of predicting either level of functioning or changes in status in these factors in this population. CA could never be considered as an index of growth and development in this deviant population.

System Findings -- Modifiers

Pre and post scores from log data for modifiers of dimensions (see Coding Manual, Appendix II) were correlated. All correlations were found to be significant, indicating an internal consistency within these modifiers. The results are presented in Table 5 below.

Table 5

Pre-Post Correlations within Modifiers (N = 40)

Modifier	<u>As</u>	<u>in</u>	<u>IND</u>	<u>⇒</u>	<u>*</u>	<u>Passive</u>	<u>Active</u>
Correlation	.38*	.72**	.70**	.36*	.39**	.53**	.64**

* $p < .05$

** $p < .01$

System Findings -- Refinements

Level Analysis of Interaction with Materials.

1. Log Data -- Ceiling age levels obtained through the level analysis of materials procedure (see Appendix I) were correlated to pre and post log weighted $\bar{x}$ scores in the Interaction with Materials dimension. These correlations were found to be significant (pre: $r = .72$, $p < .01$; post: $r = .53$, $p < .01$). This refinement of the Interaction with Materials dimension strengthened the relationship between functioning with materials and MA (pre: $r = .79$, $p < .01$; post: $r = .94$, $p < .01$). The results obtained were independent of the child's CA, indicating that for this population CA is not a critical factor in competent work with materials. Ceiling age levels for log data are present in Table 1, Appendix I.
2. Videotape Data -- Level analysis of videotape data confirmed the log data findings above. Ceiling age levels obtained from videotapes were congruent with ceiling age levels obtained from logs (pre: $r = .80$, $p < .01$; post: $r = .90$, $p < .01$). These videotape levels were also highly correlated with MA (pre: $r = .83$, $p < .01$; post: $r = .87$, $p < .01$) and with log weighted $\bar{x}$ scores (pre: $r = .75$, $p < .01$; post: $r = .59$, $p < .01$). CA was, once again, not related to functioning. Ceiling age levels for videotape data are presented in Table 1, Appendix I.

Level Analysis of Verbal Expressive Communication. Age levels in months were applied to codings of verbal expressive communications for all children. Age level data were also obtained from speech pathology records for children U - DD (N = 10). Positive correlations between language age levels and speech pathology levels were found (pre: $r = .98$, $p < .001$; post: $r = .85$, $p < .01$). Table 3, Appendix V, presents these findings. The positive correlation between age levels derived from the anecdotal records and age levels obtained through a formal speech pathology evaluation indicated that the ceiling age level is a valid means of assessing the young child's verbal expressive communication. The teachers' logs furnished ample data for analysis in this dimension.

A significant correlation was obtained between Co age level and MA (pre: $r = .80$, $p < .01$; post: $r = .89$, $p < .01$) and between Co age level and the ceiling age level for M (pre: $r = .63$, $p < .01$; post: $r = .79$, $p < .01$). As expected, CA did not correlate with the Co age levels.

The weighted mean scores for the total Communications dimension were not significantly correlated with level analysis ages. This was to be expected, since the weighted $\bar{x}$ scores were based on a combination of all gestural and vocal behavior, but age levels were derived primarily for vocal behavior. Weighted $\bar{x}$ scores were derived quantitatively, but age levels were derived qualitatively. In addition, the age levels more closely reflected highest functioning, and weighted $\bar{x}$ scores indicated an average level of functioning.

System Findings -- Demographic and Descriptive Data

Data on the total group of 40 children were examined in order to determine possible interrelationships among demographic and descriptive variables. (Variables employed in this analysis are outlined in Item 1, Appendix V.) The majority of these correlations was not significant, although some were to be expected (i.e., SES-Occupation of Head of Household: $r = .84$) and were obvious. The single group of descriptive factors which produced coherent results was the joint clinical judgments, together with MA and IQ obtained on admission. Table 4, Appendix V, presents these results. The reliability (internal consistency) of these measures led us to employ them in further analyses.

Mental Age. MA's obtained on admission were correlated with scores in the seven psychoeducational dimensions (pre and post). Table 6 below presents the results.

Table 6

Correlations between Mental Age and Pre and Post Scores in all Dimensions (N = 40)

	<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>	<u>Af</u>	<u>MO</u>	<u>mo</u>
Pre	.74**	NS	.57**	.78**	NS	NS	.57*
Post	.50**	NS	.67**	.74**	NS	NS	.59*

* $p .05$

** $p .01$

Examination of these data indicated that, in general, the child who has a high MA is also higher functioning in the dimensions analyzed in this system. It must be reiterated, however, that these are not "pure" MA scores. Tests employed by the psychology staff were not, and could not be, administered as developed and as standardized. Rather, these MA scores are a composite of items culled from various tests further modified by observation and clinical impression.

What these findings also imply is that MA can be a reasonably good indication of level of functioning on program when the group is considered as a totality. This will be further discussed in terms of the MA's limitations and strengths, as well as its use as the only tool for prediction.

Clinical Judgments. Joint clinical judgments (multi-disciplinary ratings) were also found to be strongly related to both pre status and post status scores for the N of 40. Table 5, Appendix V, presents these results. Four dimensions strongly indicated this relationship. These clinical judgments formed early in the child's stay on program were then very valid predictors of post status.

The lack of significant findings relating both MA and joint clinical judgments (delay scores) to the En, Af, and MO dimensions may be interpreted as follows: Within our population, En seems to be an important distinguishing factor only between the least competent children who show minimal or no response to the environment and the more competent children who exhibit simple relationship thinking. The largest number of children in our population of 40 reflected their awareness of the environment only at the low and intermediate levels of complexity. Additional differentiated intermediate levels could result in finer discrimination of behavior. Few subjects in our study reached and, therefore, tested the ceiling for this dimension. With a larger number of subjects and/or with children with higher MA scores, we expect a better relationship among En, MA, and joint clinical judgments.

Within the Af dimension we would suggest that (a) the system contains too many levels, and (b) the system attempts to describe too many components which are not mutually exclusive (type, intensity, quality). The immaturity of the children and the instability and impulsivity of mood and reaction of very young children confound the type of interaction viewed and coded as appropriate or inappropriate. For more mature subjects we expect these behaviors to be more stable.

Finally, the findings related to the MO dimension indicated that the degree of motor involvement was often independent of performance in other aspects of development. As previously suggested, the range and variety of motoric problems did not significantly affect the opportunity for change along other dimensions. This we firmly believe to be connected with the ratio, quality of staff, and modifications of materials, objects, and environment. A program can be fitted to test and nurture the cognitive abilities of a severely physically limited child.

Changes in Functioning -- Dimensions

Pre and post log data were examined for the total group of 40 children. Table 7 below presents these results.

Table 7

Log Data: Pre and Post Means and Standard Deviations
in the Seven Psychoeducational Dimensions (N = 40)

	<u>Pre</u>		<u>Post</u>	
	<u>$\bar{x}$</u>	<u>SD</u>	<u>$\bar{x}$</u>	<u>SD</u>
M	1.97	1.26	2.34	1.15
En	0.60	0.56	0.73	0.66
So	1.26	0.68	1.88	1.14
Co	0.75	1.03	1.43	2.03
Af	0.67	0.30	0.52	0.31
MO	0.83	0.38	1.09	0.46
mo	0.09	0.12	0.09	0.12

Even when a mean did change from pre to post, the variance was found to change simultaneously, as indicated by increases in the standard deviation. This indicated that during stay on program (for the total group) the lower levels of functioning are being eliminated. At the same time, higher levels are emerging. Thus, the range remains fairly stable for the total group, although these are shifts in low and high points. These findings conflicted with our clinical judgments that all individual children did indeed exhibit "change" while on program in all or particular areas of development.*

Since examination of individual scores revealed different patterns of change, both in terms of time and psychoeducational dimensions, it was felt that these individual changes were being missed in our statistical analysis when all the children were grouped together. Clinically we also distinguished between those children who were functioning on a "low" level and those functioning on a "high" level.

Changes in Functioning -- Modifiers

Similar findings were obtained when the total group's data were examined for changes in modifiers from pre to post. Table 6, Appendix V, presents these results.

*These findings for the N = 40 were slightly modified when a z score analysis was subsequently employed for subgroup data and then totaled. See the Total Column of Table 15a, Appendix V. Significant positive changes were found in 50% of the total N in the So ($x^2 = 8.31$, $p < .02$) and MO ($x^2 = 7.17$, $p < .05$) dimensions.

Establishment of Subgroups

In order to verify our clinical impressions and in an attempt to clarify the patterns of change exhibited by particular clusters of children, it was decided to subdivide the total study group ($N = 40$) into subgroups on the basis of level of functioning. Three subgroups emerged.

The three subgroups -- Low (L), Middle (M), and High (H) -- were established on the basis of the clinical sum delay scores (see p. 14 for derivation of this score) and the Project Director's judgment of level of functioning. The Project Director was presented with a list of the total group of 40 children rank ordered according to their respective sum delay scores and was asked to determine cut-off points for "low" and "high" functioning children. The resultant low subgroup ($N = 19$) consisted of children with scores ranging from 5 to 9, and the high subgroup ($N = 10$) was delineated with scores ranging from 14 to 19. A middle subgroup ($N = 11$) was established by virtue of exclusion from either low or high subgroup status, and the sum delay scores ranged from 10 to 13. Since the sum delay score had previously been found to be highly correlated both to MA ($r = .95$, $p < .001$) and IQ ($r = .90$, $p < .001$), the subgroups were examined to determine whether they were as highly related. It was found that the range of MA and IQ scores were significantly different for the three subgroups (see Table 8 below).

Table 8

Range of MA and IQ Scores and
Differences Among Groups for
Low ($N = 19$), Middle ($N = 11$), and High ($N = 10$) Subgroups

	<u>Range</u>	<u>Mann Whitney U Test</u>	
<u>MA:</u>			
Low	3 - 11	L vs M	U = 10.5, p < .001
Middle	6 - 24	L vs H	U = 0.5, p < .001
High	11 - 30	M vs H	U = 12.5, p < .01
<u>IQ:</u>			
Low	11 - 35	L vs M	U = 17.5, p < .001
Middle	16 - 70	L vs H	U = 0, p < .001
High	58 - 91	M vs H	U = 6.0, p < .001

An examination of CA revealed no significant differences. The following descriptors were also found to be equally distributed among the three subgroups: sex, socioeconomic status, ethnicity, medical diagnosis, severity of motor dysfunction, and type of sensory impairment.

Subgroup data were then examined to determine whether these same subgroups would be differentiated by data derived from the system as well as in terms of differences in patterns of change in the children. If coherent subgroups had been assembled, then data derived from the coding/analysis system should be able to differentiate these subgroups, and it would be expected that the children in any one subgroup would be judged to be more similar in functioning to other members of that subgroup than to children in the other subgroups, although within-group variability might still be considerable. It was felt that the changes that did indeed occur in the children might be highlighted when similarly functioning children were first grouped together and then examined.

Results for Subgroups

System Findings -- Dimensions

Log Data. Subgroup data were examined in terms of relationships between and among dimensions. The pre and post weighted mean (M, En, So, Co) and mean (Af, MO, mo) scores were correlated. Whereas for the total group of 40 children pre and post scores on the seven psychoeducational dimensions were highly correlated, when data were examined by subgroup, different patterns emerged. See Table 7, Appendix V, for results.

1. Low Group -- In the case of the low subgroup, those dimensions which remained significantly correlated from pre to post periods were those in which a low functioning or severely involved child would not be expected to make significant gains over a 3-month period of time, e.g., Gross Motor and Fine Motor and Awareness of the Environment. The Social and Communications dimensions, however, exhibited greater range and are components of a child's functioning which may override a severely limiting physical disability. With the inclusion of a gestural scale, even the low functioning child exhibited some change in the Co dimension.
2. Middle Group -- All correlations remained significant with the exception of Co. This may be attributed to the variability in competence in either or both gestural and verbal communication skills. This middle group included many children whose neurological condition was associated with severe expressive language problems. Change in many of the children in this group was restricted to change in the gestural mode. Other children who were not physically restricted to a gestural code were able to exhibit emerging verbal abilities. The intensive stimulation enhanced this developing competency to varying degrees. The correlations in the other dimensions may indicate either that all children improved significantly as a group or that little pre to post change occurred in some dimensions.
3. High Group -- In the high subgroup initial Interaction with Materials (as measured by weighted means) was not related to post weighted mean scores. However, when the pre and post ceiling age levels for Interaction with Materials were correlated, they were significant ($r = .57$, $p < .05$). The weighted mean was thus too gross a measure.

One critical finding was that the Affect dimension was not coherently related to subgroup status. This is in agreement with the previous finding of no correlation between the joint clinical judgments and Affect scores (see Clinical Judgments section, p. 34). In order to clarify findings obtained with the Affect dimension, raw scores for positive vs. negative, appropriate vs. inappropriate, and active vs. passive Affect were examined by subgroup. Percentages were calculated (i.e., % positive Affect vs. % negative Affect) and compared. Table 8, Appendix V, presents these results.

Examination of these data showed few differences among groups in proportion of positive, appropriate, or active affect. This finding may be explained as follows: Within the Infant Program maximum opportunity is given to each child to succeed and experience mastery of the environment and of materials. Therefore, positive, appropriate, and active affective behaviors are optimized. Given other conditions, for example where a low functioning child might not experience success, one would predict differential patterns of affect behavior related to level of function.

Whereas for the total sample ($N = 40$) all the hierarchical dimensions were found to be significantly intercorrelated for both pre and post periods, when this analysis was replicated within the subgroups, different patterns emerged for each group. This finding can be interpreted by two related phenomena: (a) the reduced N in each subgroup and (b) the variability in levels of functioning of children within a subgroup. Although the three subgroups do differ from one another, there is still a great amount of variability within each grouping. Tables 9a, 9b, and 9c, Appendix V, present these results.

System Findings -- Refinements

Level Analysis of Interaction with Materials.

1. Log Data -- Ceiling age levels obtained through the level analysis of materials did differentiate subgroup status. Table 10a, Appendix V, presents these results. The groups were found to be quite distinct, with no overlap in age levels across the subgroups, either at admission or prior to discharge.
2. Videotape Data -- These log data findings were substantiated by examination of videotape data. Table 10b, Appendix V, presents these results.

Level Analysis of Verbal Expressive Communication. Examination of level analysis scores in the Communication dimension also revealed the distinctive differences among subgroups. Table 11, Appendix V, presents these results.

System Findings -- Descriptive Data

Mental Age. When MA was correlated with level of functioning in the seven psychoeducational dimensions, differential patterns emerged within each subgroup. (See Table 12, Appendix V.) This is in contrast to the

findings for the total group. Thus, as one begins to categorize children in terms of actual observed level of functioning rather than on the basis of psychometric data, MA loses some of its power as a predictor. (In terms of the individual child, the usefulness of MA is even further reduced. See p. and case studies, Appendix VI.)

Changes in Functioning -- Dimensions

In contrast to the lack of significant pre-post change when the total group was examined, the subgroups did show differences from pre to post, both in terms of the average level of functioning for each group as well as inter-group variability. The pre-to-post range in each dimension differed with subgroup status. Table 7, Appendix V, presents these results.

Equating of Dimension Scores for Purposes of Comparison

In order to compare patterns of change among subgroups, a change in one dimension had to be equated with change in the other dimension. The scores on the various dimensions were not directly comparable, because only four were weighted, and each had different numbers of levels. Therefore, a means of equalizing degree of change across dimensions was utilized. Each child's pre and post score for a particular dimension was converted into a z score (standard score), based on the distribution of scores in that particular dimension. This made it possible to compare directly scores in different dimensions. Table 13, Appendix V, presents the pre and post means and standard deviations of the z scores in the seven psychoeducational dimensions for each of the subgroups. A differential pattern of significant change emerged when the data for each dimension were examined across subgroups. (See Table 14, Appendix V, for significant differences and levels of significance.) Dimensions within which significant changes in a z score occurred are depicted in Table 9, below.

Table 9

Dimensions with Significant Change (X) in z Scores for Subgroups

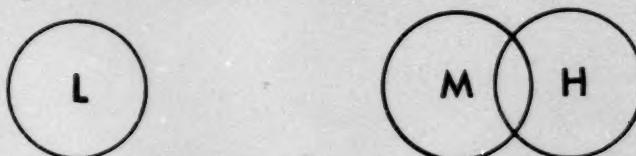
<u>Subgroup</u>	<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>	<u>Af</u>	<u>MO</u>	<u>mo</u>
Low	X	O	O	O	X	X	O
Middle	X	O	X	X	O	O	O
High	O	O	X	X	O	X	O

The low subgroup exhibited significant pre to post change in the following dimensions: Interaction with Materials, Affect, and Gross Motor Activity. The middle subgroup exhibited significant pre to post change in the dimensions of Interaction with Materials, Social Responsiveness, and Communication; and the high subgroup in Social Responsiveness, Communication, and Gross Motor.

Figures 6 and 7 (pp. 41 and 42) present a graphic display of pre and post profiles of averaged z scores in the seven psychoeducational dimensions for each of the subgroups. It can be seen that all subgroups exhibited a great degree of "scatter" in performance across dimensions, a finding that is congruent with expectations in a diverse population such as ours. Differential pre and post averaged profiles emerged for each of the subgroups. The great variability in functioning within a particular subgroup was also evident when pre and post standard deviations were examined for each of the subgroups (see Table 13, Appendix V). The subgroups were by no means homogeneous, but they were less heterogeneous than the total group of children.

In order to determine whether the subgroups differed in terms of their recorded functioning at admission and/or prior to discharge, the z scores in each dimension were compared across the three subgroups (see Table 14, Appendix V for significant differences and levels of significance for this analysis). The following findings emerged.

Interaction with Materials. During both the pre and post periods, the low subgroup was distinct in that their scores in this dimension were found to be lower than and not to overlap with those of the children in either the middle or high subgroup. In contrast, the scores of the children in the middle and high subgroups did exhibit some degree of overlap during both the pre and post periods. This is illustrated below.



Findings in this dimension were further enhanced when ceiling age levels were examined. Level analysis ceiling age scores were also converted into z scores. The findings for the low subgroup were unchanged. However, the high subgroup became distinct from the middle group in that the range of z scores was found to be significantly higher.



Awareness of the Environment. For both pre and post periods the scores of the children in the three subgroups were found to overlap significantly.

Social Responsiveness. The range of low and high subgroup scores were found to be significantly different both at admission and prior to discharge. The low and middle subgroups did not differ at admission, but the middle subgroup became distinct from the low prior to discharge.

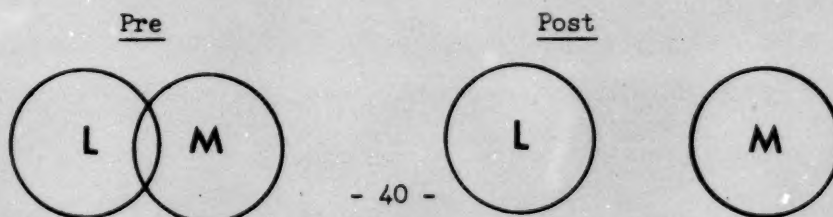


FIGURE 6

PROFILES OF SUBGROUPS BASED ON Z SCORES
WITH PERCENTILE EQUIVALENTS

Pre Period

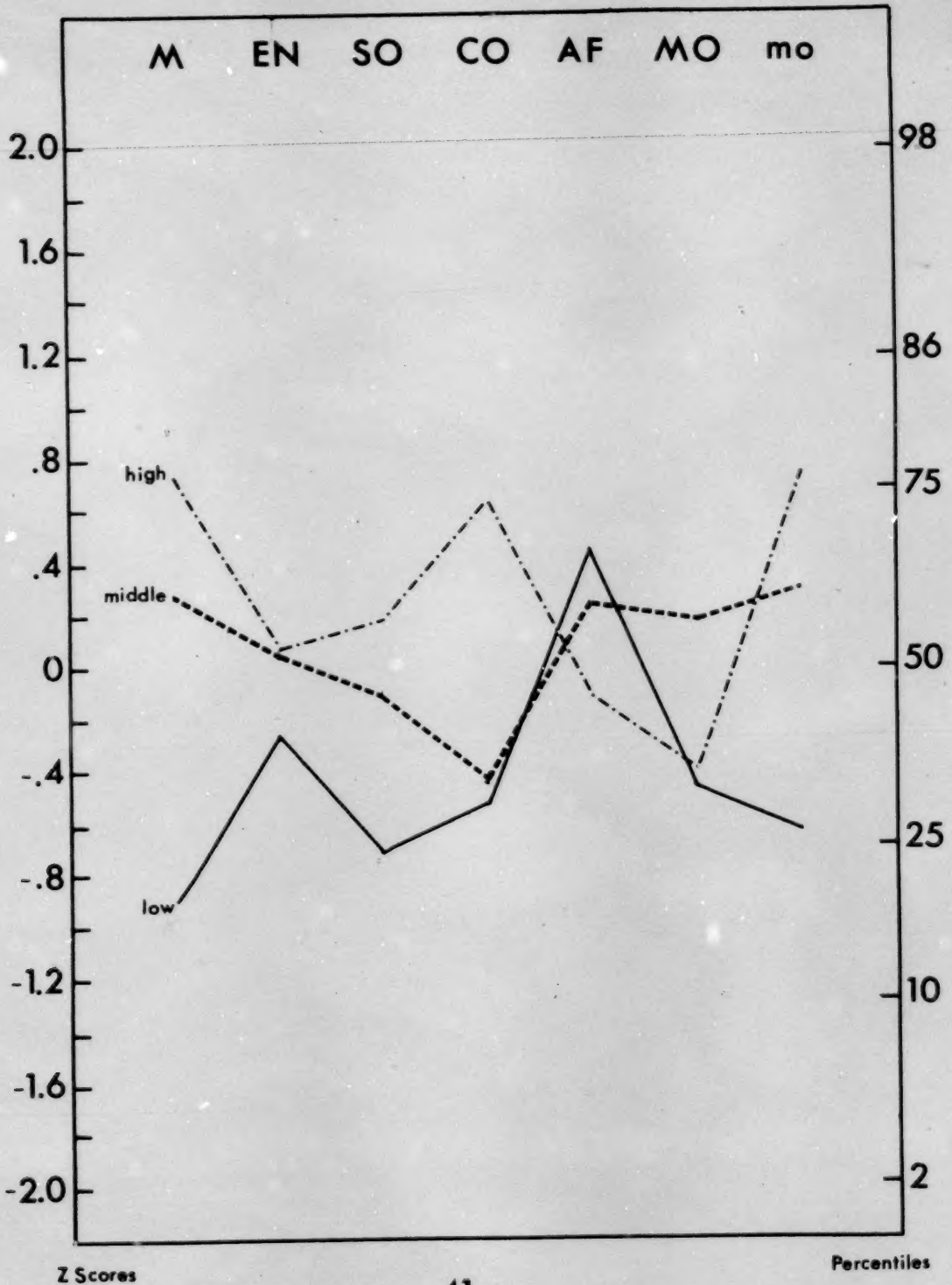
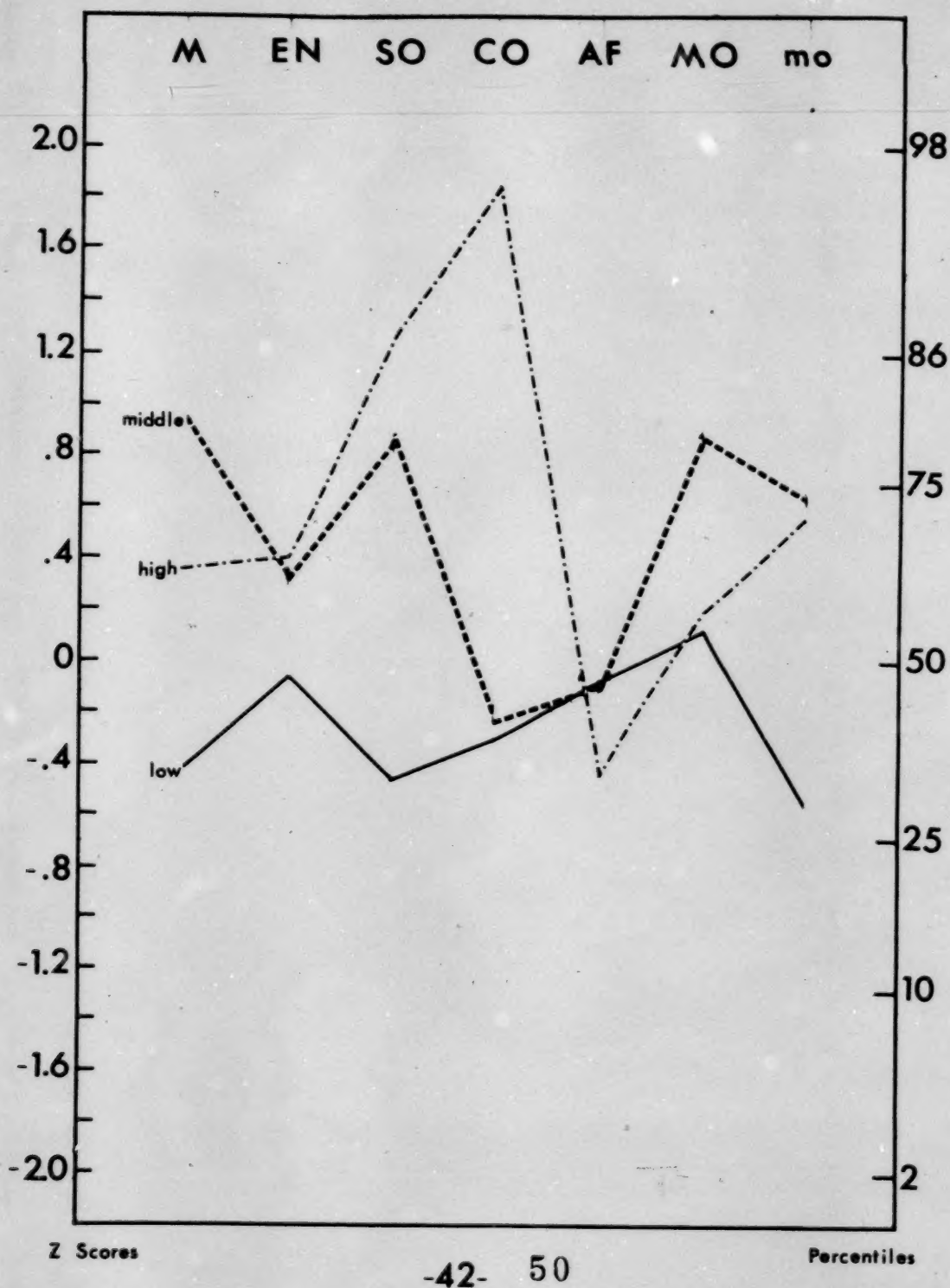


FIGURE 7
PROFILES OF SUBGROUPS BASED ON Z SCORES
WITH PERCENTILE EQUIVALENTS

Post Period



This indicates that, even though their level of functioning was similar upon admission, the children in the middle subgroup made greater gains prior to discharge than the children in the low subgroup. A comparison of the range of scores in the middle and high subgroups yielded a similar finding; although their scores were similar at admission, the high group scored significantly higher just prior to discharge, indicating that the high subgroup made greater gains on program than the middle subgroup.



Communication. For both the pre and post periods the high subgroup yielded scores significantly higher than those obtained from children in either the low or middle subgroups. During the pre period the low subgroup scores showed a trend toward being lower than those of the middle subgroup, but these two subgroups were not significantly different prior to discharge, indicating that the low subgroup children had made gains in this dimension but the middle group remained comparatively static.

Affect. For both pre and post periods the scores of the children in the three subgroups were found to overlap significantly.

Gross Motor. For all three subgroups the degree of overlap remained unchanged among the range of both the pre and post subgroup scores. The middle subgroup tended to exhibit scores higher than those of the low subgroup at admission. This trend was not evident prior to discharge, indicating that the low subgroup children made some gains in gross motor functioning while on program, as did the high group.

Fine Motor. The low subgroup was found to be distinct in that its range of scores both upon admission and prior to discharge was lower than those of either the middle or high subgroups. The children in the middle and high subgroups exhibited some degree of overlap in level of functioning on this dimension both upon admission and prior to discharge.

Changes in Functioning -- Dimensions: z Scores

The subgroup data were further examined to determine whether the direction and degree of change in the seven psychoeducational dimensions differed for the children comprising the three subgroups. Table 15, Appendix V, presents these data. A change was considered to be educationally significant if the pre and post scores differed by more than one-half of a standard deviation in either direction ($z_{\text{post}} - z_{\text{pre}} = \pm .50$). A change of less than one-half of a standard deviation was not regarded as educationally significant. This is particularly relevant when considering the population of children serviced and the limited interval of time each was exposed to a program. (The reader should be aware that the criterion of significance in direction of change described above is merely an aid in the analysis of the subgroup data and is not meant to be a hard and fast criterion for educationally significant change.)

Changes in Functioning -- Refinements: z Scores

Level analysis scores for each child were converted to z scores and then examined. The low and high subgroups were found to make significant changes pre to post (Low: $T = 19$, $p < .02$; High: $T = 0$, $p < .01$), but the middle group did not. The scores of the children in the low subgroup were found to be significantly different from those of the middle and high subgroups both at admission (Low vs Middle: $U = 14.5$, $p < .002$; Low vs High: $U = 2$, $p < .002$) and prior to discharge (Low vs Middle: $U = 19.5$, $p < .002$; Low vs High: $U = .05$, $p < .002$). Although the M5 age levels assigned to both the middle and high subgroups were comparable on admission, the children in the high subgroup were significantly higher prior to discharge ($U = 17.5$, $p < .02$).

Changes in Functioning -- Modifiers: z Scores

Examination of $\bar{X}$'s and SD's for modifiers also showed differences among groups, with differences both in average value and in variability. These data are presented in Table 6, Appendix V. The IND, Passive, and Active categories showed the most meaningful changes and were utilized in further analysis. In order to compare change across modifiers among subgroups, each distribution of scores was converted to z scores. A differential pattern of significant change emerged when the data were examined across subgroups. Table 16, Appendix V, presents these results. The low subgroup exhibited significant change in IND and Active behavior. Passive behavior did not change. The high subgroup showed uniformly significant change across all three modifiers. The middle group remained the most amorphous.

Supporting data were obtained when the three subgroups were contrasted for pre and post periods. Table 17, Appendix V, presents these results. The low subgroup was found to be distinctly different from the middle and high groups; however, the middle group did show some overlap with the high group. The child who showed a pattern of low functioning, then, might be expected to become more independent and to show an increase in active behaviors (across all dimensions) over the course of a 3-month stimulation program. Middle and high functioning children were not clearly separable on the basis of scores in these categories. Changes in these children are not expected to be as great due to their higher initial independence.

Examination of Data on Children within a Subgroup

Although quite distinct subgroups did emerge from examination of these data, the degree of variability within each subgroup precluded the use of group data to predict subtle changes. This indicated that the multi-handicapped population under study showed even greater differences than similarities. Thus, general levels of functioning (low, middle, high) will still subsume unique and individual patterns. This is illustrated by Figures 1a and 1b, Appendix V. The z scores for the two "middle" group children (G and Z) were plotted for the seven psychoeducational dimensions. Both pre and post

profiles were distinctive and quite different with regard to standing in the total population. The rationale for individual study of each child, in addition to the study of subgroups, is thus strengthened. Application of the analysis and coding system for a sample child, Child X, follows.

Results for N of 1

Data on Child X were examined (a) for correspondence or lack of correspondence between data obtained from the coding and analysis system and data obtained by multi-disciplinary evaluation (see Introduction, p. 7); and (b) for evidence of changes in functioning.

System Findings

Examination of weighted $\bar{x}$'s (hierarchical dimensions) and means (non-hierarchical dimensions) for both pre and post periods showed educationally derived data that were consistent with clinical multi-disciplinary evaluation, delay scores, and informal reports. Table 10 below presents these data.

Table 10

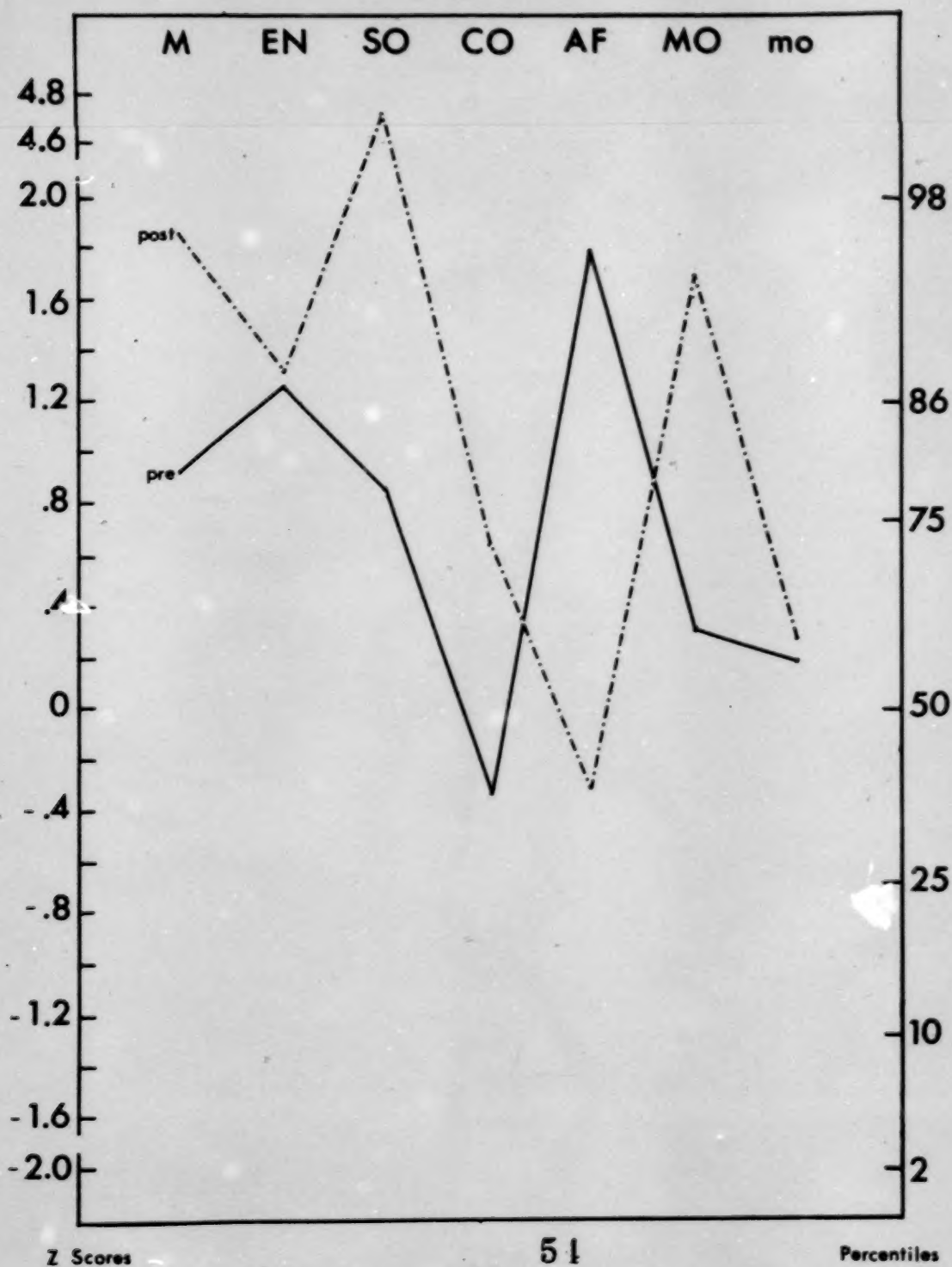
Log Data: Pre and Post Scores for Child X

	<u>Dimensions</u>						
	<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>	<u>Af</u>	<u>MO</u>	<u>mo</u>
Pre	3.29	1.42	2.39	0.54	1.14	1.09	0.11
Post	4.40	1.46	6.19	2.10	0.49	1.70	0.12

In order to allow comparison between $\bar{x}$'s with different weightings and $\bar{x}$'s which were not weighted, a series of z scores were calculated (from data on the total group). Child X's profile of z scores for pre and post periods are presented in Figure 8, p. 46.

In the pre period, Child X was above the 50th percentile (relative to the total sample) in all dimensions except Communications. Highest areas of functioning were Affect (95th percentile), Awareness of the Environment (90th percentile), and Interaction with Materials (83rd percentile). By the post period, change had occurred in all dimensions of functioning. Of great significance was the change in X's ability to communicate, where his z score is equivalent to the 70th percentile. During the course of his 3 months on program, X was encouraged to use gesture; he was thus able to make his needs known very effectively. Concurrent with this rise in communication was a dramatic increase in social responsiveness, placing X

FIGURE 8
PROFILE OF CHILD X BASED ON Z SCORES
WITH PERCENTILE EQUIVALENTS



above the 99.9 percentile for the group (see pp. 31 and 32 concerning Social Responsiveness-Communication factor). Other impressive gains were in Interaction with Materials (97th percentile) and Gross Motor Ability (95th percentile).

X's increase in gross motor ability, social responsiveness, and expressive communication was directly related to the precipitous drop in negative affect. Initially X resisted physical therapy (see case study, p. 49) and showed effects of separation. With time on the program and concomitant improvements in all areas, there was the above-mentioned marked change in the Affect dimension. These data were consistent with and supported by findings obtained prior to discharge by the multi-disciplinary team.

"Upon discharge from the Infant Program, X could assist in dressing and could feed himself with a spoon. He could now walk with a rollater, using a good gait pattern. Though psychological testing using the Bayley Scales showed only a 1-month net gain, comment was made related to X's ability to complete some tasks at the 19 to 21-month level (e.g., on request, he pointed to his shoes, hair, mouth, ear, and shirt; he replaced a square, circle and triangle in the form board)."

A narrative case history of X follows. This format permits full integration of all qualitative as well as quantitative data and, in our opinion, provides the most valid image of the child.

Case Study of Child X

Initial Data and Impressions

The initial impressions of X were of a sociable, handsome, and well dressed child. His quick smile and the gleam in his eye showed his ability to cope with a new social situation. Although his social and affective development appeared to be close to normal, his motor and language development were severely delayed. It was these delays which led his mother to seek a complete evaluation. Subsequently X was diagnosed as a child with congenital cerebral palsy, spastic diplegia type.

The etiology of this neurological disorder is presumed to be based on prematurity; X was born after an 8-month gestation. During the fifth month, his mother had gall stones removed while under a spinal anesthetic, and it is possible that this, too, might have some relationship to X's disability.

Both X and his mother, who was 20 at the time of X's admission, live together with the maternal grandmother, who was then 38 years old. X's father has maintained some connections with X's mother but will have nothing to do with the child. The impression of the social service staff was that the functioning family unit was tightly-knit and loving and was without need for counseling beyond their involvement with the Director of the Infant Program.

The affable nature of this child was confirmed by the psychologist and speech pathologist. Both therapists also commented on X's "acute awareness of the environment," which, however, interfered with obtaining an accurate indication of his level of functioning. The report by the speech pathologist notes that he was functioning at 10 to 12 months receptively. His expressive language, however, was only at the level of a 6-month old child due to some oral structural problems.

Two months prior to X's admission to the Infant Program, X and his mother met with the Director for a diagnostic work session. All activities were accompanied by extended social exchanges between X and his mother and X and the Project Director. He was able to complete each of the 10 tasks presented to him, some requiring a tremendous amount of persistence to overcome motor problems. These tasks ranged from simple activities of knocking down block towers, removing pegs and removing cubes, to more demanding tasks of inserting 1" cubes into a plastic milk bottle and replacing pegs in their holes. The mean age level derived from the level analysis on all 10 tasks was 15 months on this "screening" tape.

Data from Anecdotal Records

Anecdotal records (logs), written during the first 2 weeks X was in the Infant Program, furnished both a quantitative and qualitative description of his functioning on admission. Again, his sociability was the prominent feature of his behavior. Twenty-one percent of all behaviors were in this dimension with an almost equal proportion in the domain of affect. Both positive and negative affect were almost always appropriate to the situation.

The initial impressions of the staff are confirmed by examination of the logs. Even in those instances in which motor impairment interfered with performance, X's awareness of the goal of the task was evident; 75% of all interactions with materials were completed successfully. These included the completion of structured tasks such as removing and inserting four of six 1" pegs, inserting clothespins into a milk bottle with a 2" diameter, threading discs onto a spindle, and sorting red and yellow beads into appropriate containers. Not only did X complete these and many other tasks, but he did them with understanding and a persistence which was evident in many situations, such as the following:

"Had difficulty grasping (the 1" cubes). Dropped it on the table and adjusted his grasp. Dropped several cubes into the milk bottle this way after I told him to 'put it in.' I then offered a cube towards his right hand. He grasped with that hand, showing less difficulty in holding and inserting."

When age levels were assigned to all tasks successfully completed, X appeared to be working at close to 17 months, which is higher than reported by the various therapists.

The motor impairment which was evident in X's work with materials also inhibited his ability to explore the physical environment, with attempts at gross motor exploration rarely being mentioned during the period after admission. The absence of gross motor activity is particularly striking in this child who had such a keen visual awareness of and attention to his surroundings. It appeared that X was also aware of his limitations in this area. His anger and frustration during physical therapy interfered to such a great extent with his ability to benefit from P.T. sessions that his therapist decided to terminate these periods of formal therapy. Therefore, during the first month of X's admission to Infant Program, the infant school teachers were instructed in and took over those activities for P.T.

Educational Goals

The goals for X while in the Infant Program were developed as an extension of the competencies and needs reported during the first few weeks. He was able to color sort; thus, establishing the awareness of matching colors became a goal. This was accomplished by sorting pegs and sorting beads of various sizes. It was also clear that X had not, as yet, developed the skill of using two hands effectively. Bilateral activities such as paper tearing and pulling the tops from containers were included in activities to enable him successfully to complete a broader range of manipulations. All of these involved the development of motor abilities while, at the same time, focused on expanding X's competencies with materials.

Reports by the speech pathologist established the fact that vocalization of words would be difficult. The goals in the area of expressive language were, therefore, to develop clear and specific gestures to indicate preferences and needs. By the seventh week in the program, this was specified in the goals of that week as follows:

"To lessen his frustration in expressing demands, we will be attentive to X's first requests and then, if we do not understand, we will say so and ask him to show us. We will also ignore the crying and undifferentiated pointing that he does."

One of the underlying components of the entire program was extending X's gross motor ability to facilitate independent exploration. Activities were planned that involved specific exercises such as pulling up to a kneeling position, kicking legs while in a sitting position, and more general goals related to working on tasks while in a standing position.

Data from Quantitative Analysis of Logs Prior to Discharge

Throughout X's time in Infant Program, there was a consistent qualitative increase in all areas of functioning. There was evidence of both assertiveness and self-initiated interactions within each episode of behavior. The anecdotal records reflected that X was engaged in work with educational materials during 20% of the time. There were indications of fine motor ability emerging, this despite the spasticity related to his neurological problems.

Overall Impressions of Change

Throughout the entire program X maintained and extended his ability to work competently with those tasks presented to him. Unstructured materials and extended play with water and sand, which included scooping and pouring, became a particularly enjoyable activity. When presented with a form box, X demonstrated his ability to insert cylinders. Although rotation of puzzle pieces was difficult because of motor limitations, he could complete an individual puzzle block.

Social and affective development continued to be X's strongest areas of functioning. Increased potential for communication was nurtured by enlargement of his repertoire of gestures; these changed from undifferentiated gestures to ones which symbolically represented what he desired and needed. Those gestures were supplemented by vague, but persistent, vocalizations. The proportion of behaviors which were coded as Communication tripled by the time that X was ready to leave the program.

Another impressive gain was in the area of environmental exploration. X became extremely dextrous in the steering and manipulation of a cart designed for children with spina bifida condition (non-ambulatory). He could quickly maneuver the cart around obstacles, chairs, and other children. "He steered the cart out of the room and into the recreation room. He placed the juice in his cart and wheeled himself and the juice back to the room and directly to the table." His control of the spina bifida cart made exploration possible.

X was still limited in independent gross motor skills. By the time of discharge he could take steps when supported by the waist and he could crawl around the room. However, this area of functioning remained far below other areas.

Data from Pre-Discharge Videotape

In a psycho-diagnostic work session prior to discharge, a picture of the extent of X's competencies in a testing situation were exhibited. In each case he was aware of the desired goal of the activity. To reach this goal often required a great deal of persistence. Beyond competency, X revealed a constant and intense interest in his surroundings. This session was done in the Nursery School, a setting in which he had only been once before. There was evidence of elementary concept formation, such as clapping for himself upon completion of a difficult task (replacing beads on an abacus by matching colors). Each activity was accompanied by extended social interactions, which included a conversational interchange using both gesture and vocalization. In addition to color sorting, he could insert cylinders in a form box and identify and remove a specific piece (a chair) from a simple puzzle containing 18 different objects. The entire session reflected his independent nature with many indications of decision making and a preference for one task over another. Actual level of functioning based upon those tasks which he completed was at approximately the level of a 22-month old child, a gain of 5 months. X was now 33 months old.

After discharge from the in-patient program X was seen in the out-patient program for close to a year. Prior to relocation of X's family in New Orleans, both educational and speech programs were thus maintained.

CONCLUSIONS

This study was precipitated by the new emphasis in the early 1970's on "accountability" and the resultant need to document rigorously the proliferation of "innovative" programs supported by government funds. We have long had a strong clinical conviction that our developmental programs offered to over 1,500 multi-handicapped children in over a decade were sound. This belief was based on changes reported by the families of the children and the results of re-evaluations of the pediatric multi-disciplinary staff. This type of documentation of program, however, was no longer sufficient.

With the external stress on accountability for effectiveness in cost and outcome, professionals could be readily trapped into a narrow and constricted view of evaluation and an equally narrow, one-dimensional image of children. With this notion, evaluation would then be based simplistically on the acquisition and/or summation of single skills.

The methodologies most frequently used to record change in functioning were derived from techniques used in examining laboratory-based phenomena. These techniques are inappropriate when studying behavior in naturalistic settings, such as ours. Naturalistic behavior has an obvious closer tie to real-life situations and a greater potential for transfer than limited situation-specific responses. A more acceptable system of evaluation of program and of children had to be designed. It had to be sensitive to and mesh with the multi-faceted nature of change that is implicit in our developmental-interaction educational position. The paucity of studies based on interacting developmental dimensions may be partially attributed to the obvious difficulty in measuring the complex richness of variables in the "real world" in contrast to the relative ease in measuring individual skills acquired in a laboratory or controlled situation.

Our approach to this complicated problem was to examine and categorize parameters of development which we believe to be critical (both individually and in their interaction). This structured view of children/teacher/environment interactions was tested with naturalistic data, the source being the participating educator. A substudy attested to the accuracy and sufficiency of these data and to the transferability of the system. An experienced teacher was found to generate data comparable to data obtained from a non-participant observer and an impersonal videotape recording. Teacher-written records are a source of additional information related to teaching intent and curriculum as well as the teacher's interpretation of the child's actions based on prolonged experience with the child.

Effective implementation of this process-product analysis of change in other settings will depend upon (a) the availability and suitability of personnel, (b) delineation of specific area(s) of child development which are of concern, and (c) the questions being asked. The flexibility of the system, however, lends itself to adaptation. Our extended work with logs and videotapes as well as pilot work done with older multi-handicapped children (3 to 6 years of age) have demonstrated that the system (in total or in part) can delineate the core of an educational program as well as record change in a child. If the affect of a child or group of children is the concern of a teacher or school, only the coding related to the Affect dimension

would be applied. A language-oriented program could examine changes in Expressive Communications -- one dimension in isolation. However, this is not the approach of our program and study.

As hypothesized, the dimensions are interdependent, yielding a picture of interactive change across several dimensions. This was true, regardless of the sample size being examined (a total N of 40; or subgroups: N = 19, 11, 10; or N = 1). This finding suggests that programs should be implemented to work with multiple areas of development rather than on acquisition of segregated skills. Distinct subgroups did emerge, although within-group variability was considerable. In the child who was relatively unimpaired, all of our seven dimensions were necessary in order to describe qualitatively the child's ability and disabilities. The low functioning child, however, could be depicted through the use of groups of two or three dimensions.

Children in special education settings have often been grouped on the basis of medical diagnostic category. Within our sample medical diagnosis, per se, was no indication of a child's educational capability upon entry or at discharge. Within any medical diagnostic category the within-group variability is extreme. As such, the medical diagnosis has entry and physiological information to offer the educator.

Given the existence of "normal" variations in the acquisition of skills and the extended range of developmental milestones in the multi-handicapped, one could never expect CA to be a meaningful marker. Our findings were that CA had no relationship to the children's functioning or dysfunctioning.

The concept of MA has also been found to have its own pattern of strengths and weaknesses. The young multi-handicapped child cannot be adequately or honestly tested with any of the common standardized infant scales. None of these scales has a set of norms established on a representative sample of multi-handicapped children. Most items at the lower end of all scales require a degree of neuromuscular integrity, which our children do not possess. Administration requires adaptations of the testing situation and a concomitant weakening of standardized testing and related norms. Standardized psychometric scales are not oriented towards assessment of child-initiated actions, creative responses, and degree of activity or passivity (Hilliard, 1975), which are major concerns of our program and study. The use of an MA as a sole predictor in this population is, therefore, extremely suspect.

Within our own sample we found evidence to corroborate this theoretical critique of the MA. When the total sample of 40 children was considered, the MA was significantly related to ability. Children who "tested" at a high MA were at the upper end of each dimension's distribution of scores. However, when subgroups were delineated on the basis of clinical judgments of functioning, these MA-dimensions correlations changed and became incoherent. Within a subgroup (low, middle, high), the MA might then be related to some educational dimensions but not to others. Finally, in examining data on the individual child, the value of the MA as a predictor was almost completely lost.

Children M and O, for example, are both neurologically impaired but differ dramatically in their functioning. Both were assessed as functioning at an MA of 21 months. Different children in our program with the same MA

show widely divergent patterns of interaction, growth, and change. When teachers' daily log records were examined, clear differences in functioning emerged when applying ceiling age levels to interactions with materials. Child M scored a mean age level of 21 months, and Child O had a mean ceiling age level of 14 months. It was precisely this information that the teacher utilized in establishing the individual weekly goals and program for each child. Thus, in the case of children with impaired functioning, the use of educational materials as tools for assessment and as predictors of functioning is more informative than are medical diagnosis, CA, or MA.

The results of the level analysis of Interaction with Materials can thus serve as complementary data to the MA. The standardized test is valuable as a screening device, while the informal examination employing educational materials can serve for prescription. The model for this technique would be the diagnostic work session, which we have videotaped and analyzed. During these sessions (unlike psychometric testing), the examiner seeks to extend the child's interest and functioning to his cognitive limits without the constraints of prescribed items and/or time. The goal of the educator is to adapt and modify each task so that mastery can be achieved by the child. Thus, each task serves as a "work sample" indicative of actual competence in a learning situation. This, in a sense, is what Carver (1974) has called "edumetric" testing, where the primary purpose is to measure the growth of the individual rather than compare the individual to others.

The relevance of these types of data is underscored by the fact that they relate directly to actual classroom activities and behaviors. Individualized goals and instructional strategies can then be based on profiles of actual levels of performance. These profiles are easily translated into an individualized program. Systematic examination of patterns within a dimension allows greatest focus on the specific aspects of development which require the teacher's concentration to ameliorate a deficit area.

Our findings suggest another teacher-related value of producing log records. The need to write regular records led each teacher to a more sharp and more distinct view of the child. Intern teachers, in particular their observational abilities increased both in quantity and quality. The breakdown of behaviors into dimensions established a framework for the new teacher within which could be constructed a range and variety of learning experiences sensitively balanced to support each child's individual pattern and rate of development.

Based on our findings, we feel that it is possible to make a tentative statement of priorities for program design and components associated with specific categories and levels of dysfunction in children. A child who is low functioning across several psychoeducational dimensions can be expected to exhibit minimal changes in level of Interaction with Materials, Expressive Communication, and Awareness of Environment. In the presence of neuromuscular limitations, we can further predict only insignificant changes in Fine Motor ability. For this category of child, then, the most appropriate and least costly program may very well be one that emphasizes gross motor abilities, social responsivity, and the development of more appropriate patterns of affect. Changes in cognition would still be fostered through social, affectual, and motor interactions of the child with his environment.

We have found, however, that, although changes were limited in some of our very low functioning children, attitudinal changes in their families warranted the child's admission to our project. (See Part II on parent data for equality of shift of focus for all parents independent of level of functioning of the child.) The support for the parents, the respite from caring for the child, as well as observation of concrete gains can and do serve to improve the parent-child relationship. Parental understanding of the child's developmental status is also improved.

In the case of "middle" or "high" functioning children, a rich and intensive therapeutic program does appear to maximize growth and change. This statement is supported by the number of children from the group studied who are now in a "normal" educational setting ($N = 10$, 25%). Given this type of child, one can predict with confidence a high degree of positive change. Parenthetically, all of the children with whom we have lost complete contact were either Spanish-speaking, low functioning, or both ($N = 4$). This suggests the very special unmet needs of these children and their families. It must be stressed that, although broad subgroups did emerge from examination of the data, individual patterns of change were still unique.

On the basis of clinical experience augmented by findings from this study, what can be said about planning a program for individual multi-handicapped children? What are the critical components of an effective program? We have long believed that a high teacher-child ratio, on-going multi-disciplinary evaluation complemented by naturalistic observational records of the teacher, and consideration of interdependency among areas of development must be components of all programs. Equally critical are parental/family participation in program and decision-making, tracking of the child's progress and process of change, and child/program evaluation methodologies which are educationally based.

What have we learned about the children using this system developed to study change? It was hypothesized that all children would change as a result of exposure to this intensive program. All children did change. Change was multi-dimensional, complex, and varied in degree from child to child. At the same time there were clear limitations in change associated with degree and locus of neurological insult. We recognize that we cannot pinpoint which one or combination of the program components outlined above contributed most heavily to change in the individual child.

The program and this study have also redefined a series of issues which merit further investigation. Some of these are:

1. Within our multi-handicapped sample we were unable to scale levels of motoric growth and competence (during 3 months on program). For the non-verbal child we were not able to assign age levels for gesture skills. At what point in development do these severe restrictions in gross motor and verbal abilities interfere with the potential for future learning?

2. With the unavailability of adequately trained personnel and funds, which are, unfortunately, the reality of the educational world, how does one prepare a "uni-therapist" for educating multi-handicapped children? What are the composite of skills of associated therapies (e.g., education, speech pathology, physical therapy, and occupational therapy), which could and should be integrated experientially and academically for training developmental therapists for this age and type of child?
3. When a stimulation program for very young children is based on an "in-patient" program, does separation from the family cancel or contribute to some of the positive changes we have documented?
4. For pre-school age children, teacher/child ratio has been demonstrated to affect frequency and type of interactions between teacher and child (Diller, et al., 1973). How would a change in teacher/child ratio differentially affect a younger population? Would effects be different for high, middle, and low functioning infants?
5. What are the teacher competencies and personality characteristics needed to design and implement a stimulation program for very young multi-handicapped children?
6. Age level competencies associated with relationship thinking have been derived in this study through analysis of explicit teaching episodes of interactions with materials. Can these specific age-related educational tasks be grouped systematically and be used to formulate a program of sequential curricular goals? Can we match a program based on levels of usage of materials to parallel levels of skill in the other dimensions we have examined?

References

- Anderson, R.M., Miles, M. & Matheny, P.A. Communicative Evaluation Chart from Infancy to Five Years. Cambridge, Mass.: Educators Publishing Service, Inc., 1964.
- Bangs, T.E. & Garrett, S. Birth - 3 Scale for Handicapped Children. Houston Speech and Hearing Center. Houston, Texas.
- Barker, H.F. (ed). The Stream of Behavior. New York: Appleton-Century-Crofts, 1963.
- Barker, R.G. & Wright, H.F. Midwest and Its Children: The Psychological Ecology of a Midwest Town. New York: Harper and Row, 1955.
- Bayley, N. Bayley Scales of Infant Development. Psych. Corp., 1969.
- Bellugi, V. & Fisher, S. A comparison of sign language and spoken language. Cognition, 1972, 1, 173-200.
- Bentovim, A. Emotional disturbances of handicapped pre-school children and their families: Attitudes to the child. Brit. Med. J., 1972, 3, 579-581.
- Biber, B. & Franklin, M. The relevance of developmental and psychodynamic concepts to the education of the preschool child. J. Amer. Acad. Child Psychiat., 1967, 6(1).
- Biber, B., Shapiro, E. & Wickens, D. Promoting Cognitive Growth. NAEYC, Washington, D.C., 1971, 6.
- Birenbaum, A. The mentally retarded child in the home and the family cycle. J. Health Soc. Behav., 1971, 12.
- Bloom, L. Language Development: Form and Function in Emerging Grammars. Cambridge, Mass.: The MIT Press Research Monograph Series, No. 59, 1970.
- Boles, G. Personality factors in mothers of cerebral palsied children. Genet. Psych. Monograph, 1959, 59, 159-218.
- Brandt, R.M. Studying Behavior in Natural Settings. New York: Holt, Rinehart & Winston, Inc., 1972.
- Brown, R. & Bellugi, V. Three processes in the child's acquisition of syntax. In Lenneberg, E. (ed.) New Directions in the Study of Language. Cambridge, Mass.: MIT, 1964, 131-161.
- Caldwell, B.M. Descriptive evaluations of child development and of developmental settings. Pediatrics, 1967, 40, 46-54.
- Carver, R.P. Two dimensions of tests, psychometric and edumetric. Amer. Psych., 1974, 29, 512-518.
- Cattell, P. The Measurement of Intelligence in Infants and Young Children. New York: The Psychological Corporation, 1940.

Church, J. Language and the Discovery of Reality. New York: Random House, 1971.

Cicourel, A.U. & Boese, R.J. Sign language acquisition and the teaching of deaf children. In C.B. Cazden, V.P. John & D. Hymes (eds.) Functions of Language in the Classroom. New York: Teachers College Press, 1972.

Cohen, D. & Stern, V. Observing and Recording the Behavior of Young Children. New York: Teachers College Press, 1958.

Cook, J.J. Family limitation subsequent to the birth of a cerebral palsied child. Cerebral Palsy Review, 1963 (May-June).

Diller, L., Gordon, W.A., Hanesian, H., et al. Response patterns in brain damaged children and teaching styles. Final Report. HEW, OE, BEH, Project No. 422257, Grant No. OEG-O-70-3361, 1973.

Evert, J.C. & Green, M.W. Conditions associated with the mother's estimate of the ability of her retarded child. Amer. J. Ment. Def., 1957, 62, 521-533.

Franklin, M.B. Personal communication, 1974.

Gans, H.J. The Urban Villager. New York: Free Press of Glencove, 1962.

Gesell, A.L. The First Five Years of Life. New York: Harper & Row, 1940.

Goldberg, I. & Lippman, L. Plato had a word for it. Exceptional Children, 1974, 40, 325-334.

Gordon, I. Early child stimulation through parent education. In L.J. Stone, H.T. Smith, L.B. Murphy (eds.) The Competent Infant: Research and Commentary. New York: Basic Books, 1973, 955-960.

Gordon, R. Educational programs developed in a rehabilitation center to service and study multi-handicapped young children -- State of the art, 1974. In the proceedings of the President's Committee on Mental Retardation: Conference for Early Intervention with High Risk Infants and Young Children. College Park, Maryland: University Park Press, 1975.

Gordon, R. The design of a pre-school therapeutic playground: An outdoor "learning laboratory." Rehabilitation Monograph #47, 1972, Institute of Rehabilitation Medicine, New York University Medical Center.

Gordon, R. The design of a pre-school "learning laboratory" in a rehabilitation center. Rehabilitation Monograph #39, 1969, Institute of Rehabilitation Medicine, New York University Medical Center.

Gordon, R., White, D. & Diller, L. Performance of neurologically impaired preschool children with educational materials. Exceptional Child, 1972 (January), 428-437.

- Grim, J. (ed.) Training parents to teach: Four models. First Chance for Children Monograph, 1974, 3, 83 pp.
- Gumz, E.J. & Gubrium, J.F. Comparative parental perceptions of a mentally retarded child. Amer. J. Ment. Def., 1972, 77(2), 175-180.
- Haeussermann, E. Developmental Potential of Preschool Children: An Evaluation of Intellectual, Sensory, and Emotional Functioning. New York: Grune & Stratton, Inc., 1958.
- Hall, W.T. Physical handicap and family stress. Cerebral Palsy Review, 1963 (July-August), 9-11.
- Hilliard, A.G. The strengths and weaknesses of cognitive tests for young children. In J.D. Andrews (ed.) One Child Indivisible. NAEYC, Washington, D.C., 1975, 17-33.
- Hunt, J.McV. Parent and child centers: Their basis in the behavioral and educational sciences. Amer. J. Orthopsychiat., 1971, 41(1), 13-38.
- Hutt, S.T. & Hutt, C. Direct Observation and Measurement of Behavior. Springfield, Illinois: Charles C. Thomas, 1970.
- Irwin, O.C. Language and communication. In P.H. Mussen (ed.) Review of Research Methods in Child Development. New York: Wiley, 1960, 487-516.
- Karnes, M.B., Teska, J.A., Hodgins, A.S. & Badger, E.D. Educational intervention at home by mothers of disadvantaged infants. Child Development, 1970, 41, 925-935.
- Kass, E.R., Sigman, M., Bromwich, R. & Parmelee, A.H. Educational intervention with high risk infants. Paper presented at the Conference on Early Intervention for High Risk Infants and Young Children, May, 1974, Chapel Hill, North Carolina. Sponsored by the President's Committee on Mental Retardation and the Association for Childhood Education International.
- Kleinberg, W. & O'Connor, P.A. Appraising the effectiveness of a simple educational approach to problems of retardation and behavior in childhood. Clinical Pediatrics, 1972, 545-548.
- Koch, R., Graliker, B.V., Sands, R. & Parmelee, A.H.Sr. Attitude study of parents with mentally retarded children. 1. Evaluation of parental satisfaction with the medical care of a retarded child. Pediatrics, 1959, 23, 582-584.
- Kogan, K.L. & Tyler, N. Mother-child interaction in young physically handicapped children. Amer. J. Ment. Def., 1973, 77(5).
- Langner, T. & Michael, S. Life Stress and Mental Health. New York: The Free Press of Glencoe, 1963.
- Lenneberg, E. Biological Foundations of Language. New York: John Wiley & Sons, Inc., 1967, 128-129, 180-181.

- Levenstein, P. Cognitive growth in preschoolers through verbal interaction with mothers. Amer. J. Orthopsychiat., 1970, 40(3), 426-432.
- Lewis, M.M. Language, Thought & Personality in Infancy and Childhood. New York: Basic Books, 1963.
- MacDonald, J.B. An evaluation of evaluation. Urban Review, 1974, 7, 3-14.
- Marshall, N.R. & Goldstein, S.G. Effects of three consultation procedures on maternal understanding of diagnostic information. Amer. J. Ment. Def., 1970, 479-482.
- Matheny, A.P.Jr. & Vernick, J. Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived? J. Pediatrics, 1969 (June), 953-958.
- McCarthy, D. Language development. Monogr. Soc. Res. Child Dev., 1960, 25(3), 5-14.
- McNeill, D. Developmental psycholinguistics. In F. Smith & G.A. Miller (eds.) The Genesis of Language. Cambridge, Mass.: MIT Press, 1966, 15-84.
- Morris, D. The psychological management of handicapped children in the first year of life. In J.G. Howells (ed.) Modern Perspectives in Psycho-Obstetrics. New York: Brunner/Mazel Pubs., 1972.
- Northcott, W.H. The integration of young deaf children into ordinary educational programs. Exceptional Children, 1971, 38, 29-32.
- Polansky, N.A., Boone, D.R., DeSaiz, C. & Sharlin, S.A. Pseudostoisicism in mothers of the retarded. Social Casework, 1971 (December).
- Poznanski, E.O. Emotional issues in raising handicapped children. Rehab. Literat., 1973, 34, 324-326.
- Quick, A.D., Little, T.L. & Campbell, A.A. Lesson Plans: Guides to Teaching Preacademic Skills. Project MEMPHIS, Memphis State University, Memphis, Tennessee, 1973.
- Quick, A.D., Little, T.L. & Campbell, A.A. The Training of Exceptional Foster Children and Their Foster Parents: Enhancing Developmental Progress and Parental Effectiveness. Project MEMPHIS, Memphis State University, Memphis, Tennessee, 1973.
- Rowen, B. The Children We See: An Observational Approach to Child Study. New York: Holt, Rinehart & Winston, Inc., 1973.
- Sanford, A.R. Learning Accomplishment Profile. Chapel Hill, North Carolina: University of North Carolina Printing Department, 1974.
- Schaefer, E.S. & Bell, R.Q. Development of a parental attitude research instrument. Child Dev., 1958, 29, 339-361.
- Shapiro, E. Educational evaluation: Rethinking the criteria of competence. School Review, 1973, 81, 523-549.

- Shearer, M.S. A home based parent training model. In J. Grim (ed.) Training parents to teach: Four models. First Chance for Children Monograph, 1974, 3, 49-62.
- Shere, E.S. Modes of child-rearing in cerebral palsy: Effects upon the child's psychological development. The Israel Annals of Psychiatry and Related Disciplines, 1971, 9, 52-59.
- Sheridan, M. The Handicapped Child and His Home. London: National Children's Home, 1965.
- Shirley, M.N. The first two years: A study of twenty-five babies. Vol. II: Intellectual Development. University of Minnesota, the Institute of Child Welfare, 1933, 47-72.
- Tew, B., Lawrence, K.M. & Samuel, P. Parental estimates of their physically handicapped child. Dev. Med. Child Neurol., 1974, 16, 494-500.
- Wiegerink, R. & Parrish, V. A parent implemented preschool program. In J. Grim (ed.) Training parents to teach: Four models. First Chance for Children Monograph, 1974, 3, 65-75.
- Wolfensberger, W. Counseling the parents of the retarded. In A.A. Baumeister Mental Retardation: Appraisal, Education and Rehabilitation. Chicago: Aldine Pub. Co., 1967.
- Wolfensberger, W. & Kurtz, R.A. Measurement of parents' perceptions of their children's development. Genet. Psych. Monogr., 1971, 83, 3-92.
- Wood, T.M. (ed.) Infant Stimulation Curriculum. Columbus, Ohio: Ohio State University, 1974.
- Wright, H.F. Recording and Analyzing Child Behavior. New York: Harper & Row, 1967.
- Zimiles, H. Problems of assessment of academic and intellectual variables. Revised version of paper presented at the American Educational Research Association meeting, symposium on "Problems of Educational Evaluation Confronted in Head Start." Chicago, February, 1968.
- Zuk, G.H., Miller, R.L., Bartram, J.B. & Kling, F. Maternal acceptance of retarded children: A questionnaire study of attitudes and religious background. Child Dev., 1961, 32, 525-540.

Refinements of the coding system were made during the years 1973 - 1975. An age level analysis of Interaction with Materials and of Verbal Expressive Communication yielded mean ceiling age levels in these dimensions. The Communications dimension was refined to include both vocal and gestural components. The Awareness of Environment dimension was refined.

Interaction with Materials -- Age Level Analysis

Problem

During the first year of the study, when the sample size was small (N analyzed = 10), comparisons among children were based upon rankings. It was observed at this time that in some cases pre to post rankings based on weighted frequency of total interaction with materials responses resulted in a picture of change in a child which was not in accord with clinical judgments. It was decided, therefore, to focus specifically on one level of the hierarchy in an attempt to delineate rankings and change in terms of the specific demands of a task and the age at which a competence should be expected to exist.

Method

Initially all M5 level interactions in the coded logs were identified (N of M5's = 307), and extensive annotations were made of the nature of the successfully completed task. Then the standardized developmental norms of Bayley (1969), Gesell (1940), Cattell (1940), and Hauessermann (1958) were examined. Standardized norms were available only for 70 tasks. Specialized and adapted materials are constantly used in the Infant Program because of the specific needs of these children. Therefore, most tasks are not to be found within the standardized scales.

On those items which were not found in the literature, age ranges were assigned by the Project Director and the staff psychologist based on clinical experience. They independently rated the remaining 237 tasks in terms of a 6-month zone of competence. The measure used was the age at which failure to complete the task would indicate lag. This was seen as the upper limit of a 6-month zone rather than the median age for completion. Both high and low points assigned were found to be identical for 33% of the tasks. Mid-points fell within 3 months of each other in 62% of the cases. In 95% of the cases there was agreement within a 6-month interval. In those cases in which agreement did not exist, a re-examination of the items clarified that this discrepancy was due to varying interpretation of the material or nature of the task. Age ranges for the remaining 5% of the tasks were jointly decided upon by the staff psychologist and the Project Director.

For each of the 237 items (non-standardized) a ceiling age was then assigned. The ceiling was operationally defined as the age at which one would be concerned if a child could not successfully complete the designated task. The ceiling age is the upper limit of each age range. These ceiling ages were then applied to M5 codings for these 10 children's log data, were used

to obtain a "mean age level," and were found to yield a more realistic picture of these children by adjusting their weighted scores. The mean ceiling age level was obtained by using only a single instance of competent performance with any given material during a time period or on a videotape. Table 1 (p. 64) presents mean ceiling age levels for both log and videotape data.

Communication Dimension -- Refinement and Age Level Analysis

Problem

Analysis of early codings along this dimension (previously labeled Expressive Language), indicated that the weighted means derived from these codings frequently gave a false picture of higher functioning to a child which was not matched by his/her performance along other hierarchical dimensions. The original 11 levels in this dimension yielded much higher weighted mean scores. Revision of the dimension was required by assignment of the same weighting to several levels or elimination of those categories which were not true indicators of expressive language. A weighting scale more similar to that of the other hierarchical dimensions was devised.

Method for Refinement

Examples of behaviors coded as Expressive Language were taken from reliability logs on all children. These codings were reviewed in conjunction with an external consultant* and the staff speech pathologist**; relevant literature was also considered in this examination of coding categories. As an outgrowth of this, new guidelines were developed.

The revised dimension included parallel hierarchies of the vocal and gestural modes; thus, corresponding levels of communication were given equal weight.

Co 1

Vocal Mode

UV
DB
AW/W
WS
WS+
WS→

Gestural Mode

UG
DG
SG

SG+
SG→

Ccl = Absence of communication

UV = undifferentiated vocalization
DB = differentiated babbling
AW = approximates word
W = word, single
WS = words, phrase
WS+ = sequential speech
WS→ = connected discourse

UG = undifferentiated gesture
DG = differentiated gesture
SG = symbolic gesture, single
SG+ = elaborated symbolic gesture
SG→ = connected symbolic gesture

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** Mrs. Judy T. Cronheim

Table 1

Level Analysis

Mean Age Levels in Months for Logs and Videotapes

	<u>Logs</u>		<u>Videotapes</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
A	23	25	24	24
B	12	12	8	9
C	22	25	23	24
D	12	13	9	12
E	0	14	11	12
F	17	26	22	25
G	19	27	17	23
H	7	9	9	11
I	13	18	13	17
J	23	18	15	15
K	20	26	24	25
L	9	10	11	11
M	21	23	18	23
N	8	11	10	14
O	14	19	15	16
P	14	18	14	15
Q	17	17	0	0
R	10	11	11	11
S	12	12	8	8
T	18	19	17	22
U	7	14	8	14
V	16	16	14	15
W	19	20	15	16
X	17	15	15	22
Y	11	11	12	10
Z	18	18	17	15
AA	15	13	12	13
BB	16	17	12	16
CC	21	24	26	28
DD	11	14	11	12
EE	14	13	15	13
FF	23	27	17	27
GG	8	11	12	13
HH	12	11	11	12
II	13	15	12	15
JJ	8	10	12	12
KK	12	12	0	10
LL	13	12	13	11
MM	10	11	9	10
NN	22	22	21	25

Results -- Gestural Mode

Relatively few investigators have focused on the emergence and development of gesture as a communicative mode. Those studies that do exist have concerned themselves primarily with the sign language of young deaf children and its development and structure (Bellugi & Fisher, 1972). These children initially develop a "natural" gesture code upon which formal manual sign language is superimposed (Cicorel & Boese, 1972). The gestural mode now incorporates behaviors extending from the undifferentiated gesture (Ug), which is not situation-specific (analogous to early vocalizations), to the extended use of symbolic gesture (SG).

Undifferentiated Gesture (UG). The most primitive type of gesture, this includes vague generalized movements not specific to situations but which are seen as attempts to communicate. These begin to emerge at about 2 months in the normal infant (Morris, 1972).

Differentiated Gesture (DG). These involve gestures which are specific to a situation. In the normal child this emerges at about 9 months and includes such things as "waving bye-bye" (Anderson, Miles, & Matheny, 1963).

Symbolic Gesture (SG). Behaviors in this category include symbolic depictions specific to situations, indicating properties comparable to words, such as miming, to indicate a desire for a drink.

Elaborated Symbolic Gesture (SG+). A sequence of symbolic gestures analogous to a phrase.

Connected Symbolic Gesture (SG→). A continuous interchange of gesture (i.e., a gestural conversation).

Results -- Vocal Mode

More research has been conducted on the development of speech than on the development of gesture. As noted by Franklin (1974), the earliest sounds are related to comfort/discomfort and are not preliminaries to speech development.

Undifferentiated Vocalization (UV). The most primitive category of the vocal mode hierarchy is the undifferentiated vocalization (UV, previously labeled UB). Such vocalizations or babbling consist of polysyllabic, repetitive sounds. It is generally agreed that the age of onset of these vocalizations is between 3 to 5 months in normal children (Lenneberg, 1967; Shirley, 1933). The phonetic quality of these utterances has been extensively and thoroughly analyzed by Irwin and others (Irwin, 1960). Babbling occurs within a social context and in response to social stimulation, with mothers often reporting that their infant "babbles back when talked to" (McCarthy, 1960; Shirley, 1933).

Differentiated Babbling (DB). Towards the end of the first year of life, vocalization becomes more differentiated with particular sounds or sequences of sounds appearing in association with specific purposes or in

certain specific types of situations (Lewis, 1963). Babbling becomes more extensive, and expressive sounds whose inflection and intonation are similar to that of adult speech appear (Anderson, Miles, & Matheny, 1963; Shirley, 1933).

Approximates Word/Single Word (AW/W). In Shirley's (1933) study of 25 babies the median age at which the first comprehensible word was spoken in the examiner's presence was 60 weeks. Although word approximations are coded separately (AW), they are numerically and statistically grouped with single-word utterances. This is based on the overlap between these two categories (Church, 1971). Expressions such as "allgone" are categorized as single-word utterances if neither of the parts is used alone or in combination with other words. When there is no evidence of a syntactic relationship between adjoining words (i.e., peach/Daddy), this is viewed as two separate single-word utterances (Bloom, 1973). With growth and development vocabulary size increases and syntax develops.

Words (WS). The first evidence of syntactic structure is the two- or three-word combinatorial utterance (Brown & Bellugi, 1964). These are phrases rather than complete sentences. The age of onset is generally agreed on an 18 months (Lenneberg, 1967; McNeill, 1966).

Sequential Speech (WS+). Speech then becomes more clearly sequential and more grammatically correct. Although the ideas being expressed are still relatively simple, there is evidence of nouns and verbs, subject and object, in these utterances. This normally develops during the second year of life (Gesell, 1940; Shirley, 1933).

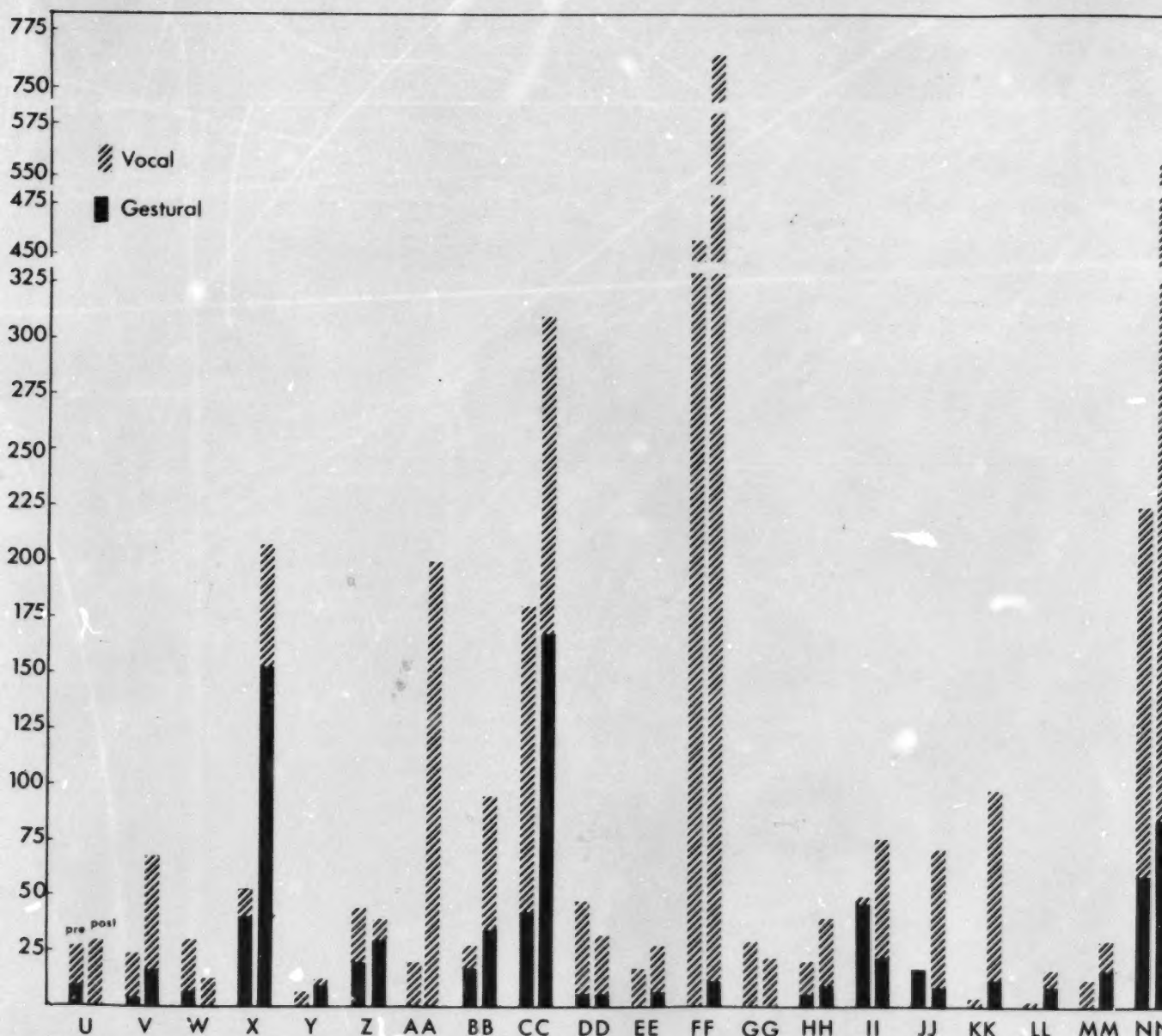
Connected Discourse (WS→). This is a stage of real exchange or conversation with another. By 36 months the child can utter a negative statement and use pronouns, adverbs, adjectives, and prepositions (Anderson, Miles, & Matheny, 1963; Bangs & Garrett, 1973).

Discussion and Implications of Refinement

The revised Communications dimension (see Appendix II for definitions and examples) is more applicable to our diverse population. In a normal population vocal utterance becomes the primary communicative mode. Nonetheless, primitive gestures (i.e., "waving bye-bye"), representational gestures, and "charade"-like enactments can be effectively employed when necessary. The gestural mode does not, however, continue to differentiate in the normal population and is comparatively rare once the vocal mode has developed. In hearing-impaired populations or in individuals who are speech impaired, the gestural mode can become an effective alternate mode of communication. In these cases it does differentiate and can be used to convey symbolic information for extended conversation. By separating the vocal and gestural modes, each can be separately weighted and analyzed, and a better picture of a child's range of functioning along this dimension may be obtained. Figure 1 (p. 67) depicts vocal and gestural contribution to expressive communication.

Figure 1
EXPRESSIVE COMMUNICATION
 Gestural & Vocal Contribution to Total Score
 For Pre & Post Periods

N = 40



-67-

Level Age Analysis for the Verbal Communication Dimension

Problem

Once the dimension was revised, the assignment of ceiling age levels to communications codings was refined. Levels could then be used to arrive at a mean age level for the child's ability to communicate.

Correlations between the child's vocal language and tested MA had been consistently high. By extracting an age level from our data we hoped to increase the power and predictive value of this relationship and to suggest an alternative means of testing the infants' level of communication.

Method for Revision

In consultation with our external consultant and our speech pathologist, the following tentative ceiling ages were first established. As was the case for the level analysis of materials, the ceiling age was defined as that chronological age at which one would be concerned if a skill/ability had not as yet developed.

Tentative Ceiling Ages -- Vocal Mode:

Undifferentiated Vocalization (UV)	6 months
Differentiated Babbling (DB)	12 "
Approximates Word/Single Word (AW/W)	20 "
Words/Phrase (WS)	30 "
Sequential Speech (WS+)	36 "
Connected Discourse (WS→)	42 "

The size of the child's vocabulary was also incorporated into this system. Higher numbers of single words will raise the functioning level of a child who is not using phrases as yet but has an extensive vocabulary.

As very little normative data exist for gesture, the assignment of ceiling age levels was not feasible for the gestural mode.

Awareness of Environment -- Refinement of Dimension

Problem

In the first year of the study analyses involving the dimension of Awareness of Environment exhibited low levels of significance (see Table 7, Appendix IV). This suggested that the dimension should be refined, eliminated, or become a modifier of other dimensions. A decision was made to refine and redefine the dimension's concept and hierarchy rather than eliminate it, as it is intimately involved with adaptive behavior.

Method

The refinement of the dimension of Awareness of the Environment first involved selecting examples which had been coded in this category in the previous logs. These examples were taken from the reliability logs of 10 children randomly selected from the first 20 children in the study. A total of 60 logs were examined, six logs for each child. Each behavior previously coded as Awareness of Environment at the 1, 2, or 3 level was written on a separate index card. On the basis of a set of tentative guidelines, agreed to by project personnel after conferring with our external consultants, these logs were then re-examined with the intention of selecting behavior previously not considered under the former definitions. This procedure yielded a total of 143 incidents. (These tentative guidelines expanded the previous three levels to six levels, included those behaviors previously subsumed under Sensory Responsiveness, and added those behaviors which reflected levels of cognition not previously incorporated in the dimension of Awareness of Environment.)

The next stage was to formulate firm definitions for each level. By sorting each card that represented an activity into six different groups, commonalities appeared to emerge. This process was repeated by four individuals: the Project Director, the coordinator of evaluation research, the senior project assistant, and the two pre-school teachers (who arrived at a single decision). For 78 of the 143 behaviors, all four agreed, either identically or with one of the four disagreeing by only one level. These 78 cards were then regrouped by levels. The definitions which are found in Appendix II are based on the similarities in behaviors found in each of the six groups.

These new codings were applied to the behaviors noted on the cards. Of 16 behaviors which previously were not coded as En, 13 were considered to be at levels which indicated awareness of causality and its application -- levels 4, 5, and 6. Thus, the new coding system appears to be better able to pinpoint a child's functioning with regard to his awareness of the environment, especially in terms of higher levels of functioning in this dimension.

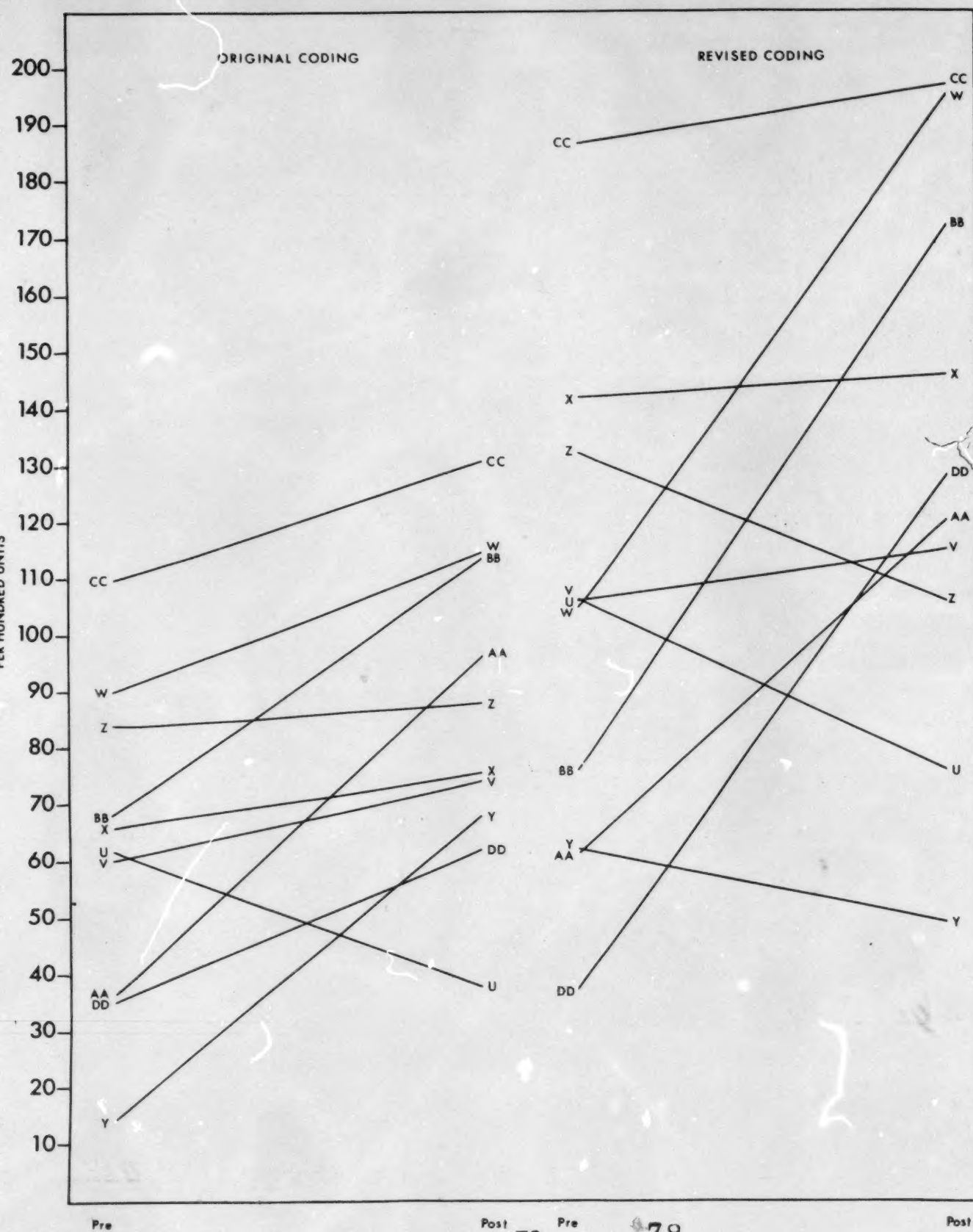
Application of Revised Codings for the Dimension of Awareness of Environment

Analysis of the data was continued to determine if the revised codings yielded greater differentiation for the total group of children. Another area for analysis was whether the revised positions of the children in this dimension approximated clinical impressions. Therefore, the logs of children U - DD were recoded for the environment dimension and retallied. Correlations were then performed between the scores obtained from the original coding and those obtained from the revised coding. Figure 2 (p. 70) presents results of this application.

Results of Application of Revised En Coding

Pilot application of these guidelines indicated that these codings were more sensitive to the range in levels of functioning. These new codings

REFINEMENT OF AWARENESS OF ENVIRONMENT DIMENSION



yielded a greater frequency of responses and higher weighted mean scores. The greater frequency was due to the inclusion of items which had previously been coded as Sensory Responsiveness (SR) as well as the coding of additional behaviors which were previously uncoded and could only be annotated. The increased weighted means were partially a reflection of the weighting of the newly created levels. Not only did the new coding yield greater differentiation in the group on a numerical basis but also on a clinical basis. This was especially true with those more mature behaviors which demonstrate initial awareness of causality and the child's ability to apply previous experience to new situations (levels 5 and 6). As if evident in Figure 2, the group as a whole did not change in relation to each other. Their relative rankings remained essentially the same. Significant correlations were found between the old pre En and the new pre En ($r = .71, p < .05$), as well as between the old post En and the new post En ($r = .78, p < .01$).

M5

Uses materials in terms of the task demand as structured by the teacher or as designed into the material.

Examples:

He dipped the paint brush into the jar and made some strokes on the paper.

I gave her the cylinders and squares, and she quickly placed them into the appropriate places in the form box.

Handed her mushroom pegs already in board and clear plastic tube for insertion. She removed pegs and dropped them into tube.

M6

Extended use: Awareness of intended goal but extends activity beyond the task demand.

Examples:

After he replaced the square in the form board, he removed it and began stacking all the other square forms on top of it.

When we had finished using the musical instruments, she picked up her drum, hit it with her hand, then rolled it slightly on the floor. She continued this until she reached the other end of the room.

M7

Creative use: Child indicates an awareness of intended use of material but chooses to use in a manner beyond conventional uses or activities.

Examples:

He finished his painting, and when I said it was time for a snack, he offered the doll a jar of paint and said, "Juice?"

She opened the book, inverted it and stood it on the floor so that it formed a tent-like tunnel structure. Then she pushed the toy car back and forth so that it entered at one end and came through the other end of the tunnel.

Rather than restacking the large cartons, she reached for one and held it close to her as if she were hugging a baby.

Coding Definitions and Examples

I. Dimensions

A. Hierarchical Dimensions --

1. M INTERACTION WITH MATERIALS: Extent to which child demonstrates goal-oriented activities with materials.

M1 No overt response to a material.

Examples:

She did not notice the doll that I placed directly in front of her.

I pushed the large wheeled pull-toy towards him. He did not respond.

M2 Limited contact: visually focuses, mouths, or touches material.

Examples:

I gave him the lock box. He touched the knob.

J gave him a teddy bear, which he mouthed.

M3 Exploration, experimentation, trial and error: manipulates, handles, smells, tests to clarify the functional attributes of a material.

Examples:

She did not stack blocks but did take one block in each hand and bang them together.

He placed the circle form piece, first in one section, then in another section, until it fit appropriately.

M4 Demonstrates understanding of a task demand but is unable to complete the task independently as the result of an impairment.

Examples:

He was able to locate and place two of the three form pieces correctly in the form board.

I offered discs and double-spindled board with short spindle only. He seemed to understand the goal of threading after I demonstrated, but could not replace because of motor problem.

2. En

AWARENESS OF ENVIRONMENT: Refers to all aspects of the child's behavior which reflect his awareness or lack of awareness of the environment. This ranges from basic responses to sensory stimuli to the comprehension of causality and its application.

En1 No overt response to stimulation: Child is not aware of events in the environment.

Examples:

She did not respond when I tickled her foot.

We began some group singing. He didn't react, just continued to look at his hands.

En2 Awareness of sensory stimulus: Reacts to events occurring in the environment.

Examples:

She smiled when the record player was turned on.

She followed the light from the flashlight as it moved across the floor.

En3 Exploratory behavior: Indicates curiosity about changes in the environment.

Examples:

He spontaneously pushed her stroller back and forth and inspected the wheels.

We walked down the hallway, and he stopped to look in the doorways.

En4 Awareness of relationships and sequences: Child indicates awareness of associations or relations between object and word, function and object, objects with one another, location with an object, sequence of events, etc.

Examples:

When done with them, he returned both sets of pop-up people to their appropriate storage place in the cabinet.

When the physiotherapist appeared at the door, he knew she had come to take him to his physical therapy session. He immediately placed his hand in hers and pulled toward the door.

En5 Extended awareness of relationships: Anticipates and tests out a relationship to achieve desired result.

Examples:

He tried to remove the puzzle from the shelf; when he couldn't reach, he pulled out a chair and climbed on it.

He sucked his bottle, removed from mouth, shook until bubbles formed. He tilted bottle so he could watch bubbles. When they stopped forming, he shook again.

En6 Transfers general knowledge of relationships: Indicates understanding of causality in specific situations.

Examples:

He put the shoe on the doll's foot. He then removed it and tried to put it on his own foot, intermittently looking up at me and laughing.

He turned the light switches off and on and looked at the lights to see the effect he was making by turning the switches.

3. So

SOCIAL INTERACTION: Responsiveness to people.

The letter to the right of the So coding specifies the person with whom the child is interacting:

A = Adult (teacher or therapist)
As = Adults
AP = Parent
C = Child
Cs = Children

So1 No overt response to person or no response to being comforted by an adult.

Examples:

So1 A He cried very hard regardless of where I walked with him or what I did.

So1 A I touched her arm, but she continued to stare at the floor.

So1 AP His mother walked to the table, but he did not smile, continued to look at me.

So2 Initial awareness: Brief response to person. Acknowledging presence of others by greeting, touching, contact, or vocalizing.

Examples:

So2 AP He looked at his mother when she talked to him.

So2 C He watched her play with the tray of salt.

So2 A When I entered the room, he looked up and smiled at me.

So3 Brief interaction: Child indicates the need for the aid of another individual or responds to assistance or contact given by another.

Examples:

So3 A He held out his hand for a cookie from me.

So3 C She reached up to his face, touched his eyes, nose, mouth, and cheeks.

So3 AP When her mother picked her up and held her, she stopped crying.

So4 Responds to request: Follows simple instructions.

Examples:

So4 A I asked her to toss the paper cup into the basket and she did.

So4 A She reached for the tray of water but waited for another tray when she was told that another child was using the first tray.

So5 An extended interaction: Interrelating or continuing interaction with someone involving cooperative, give-and-take behavior, often in a group situation.

Examples:

So5 A He and I rolled the ball to each other for awhile. I said, "Ready?" He extended his arms and burst into laughter each time the ball came to him. He then tried to imitate the word "ready" as he returned the ball to me.

So5 C She and Mary took turns playing peek-a-boo with the cloth.

4. Co

EXPRESSIVE COMMUNICATION: Includes all attempts of the child to verbalize or use gestures as a means of communicating.

Col

Child does not attempt to communicate in a given situation in which the particular child would ordinarily respond with either some type of vocalization or gesture.

Examples:

She usually said "ai" when I came in. Today she looked at me and said nothing.

I sat down next to him, asking what he'd like to do. Again there was no response.

He would not shake his head "yes" for me when I asked if he wanted to get out of the crib.

Vocal Mode

UV

Vocalizations which are not specific to a situation. The sounds produced are undifferentiated and do not form a distinguishable pattern.

Examples:

He greeted me with babbling.

She spontaneously started making vowel sounds ("ah, eh").

He made many babbling sounds while we were in the playground.

As she played with the squeaky ball, she produced a variety of sounds.

DB

Phonetic forms which produce differentiated sounds which are stabilized for specific situations and/or have differentiated intonation patterns. Either a single syllable or a poly-syllable pattern.

Examples:

He always said "hoop" when I arrived.

He used his new emphatic "ah" to let the others know that he was there.

She said "gu, gu" with the same intonation as when I said to her "good girl."

AW Child's vocalizations approximate actual words. (This is considered to be at the same level as single words.)

Examples:

He said "bottuh" when he saw the bottle on the table.

We played "shake-the-rattle" game, and he shouted "ake, ake" as he shook his rattle.

He said, "Ni, ni" for "nice".

He said "nana" after hearing "banana" several times.

W Produces a clearly differentiated word. (This overlaps with AW periods and includes "borderline" words and pairs of words which the child seems to consider as a single word; e.g., all gone.)

Examples:

She asked for a "cookie".

He pointed to the picture and said "dog".

As soon as I came near him (in crib), he said "out".

She kept screaming "go-go, go-go" (Chinese for "brother").

WS Combines a series of words in a phrase with some evidence of syntactic organization.

Examples:

He said, "I go out."

She extended her arm holding the cup and said, "More juice."

He asked for "my dog."

He started calling me "mom". Then he said, "Come here."

WS+ Combines words into a complete sentence of more than three words.

Examples:

He said, "Today my birthday. I be three."

She saw the teacher and said, "Today I go to the playground."

He said, "Bye, see you later," when I left.

He greeted his mother with "You came. I called you. You came."

WS → Child is engaged in continuous verbal interchanges or uses more elaborated sentences.

Examples:

He looked at the boat on the river and said to me, "Look at dat. What dat?" I answered, "That's a boat." He repeated, "Boat. What it do? Where it going?"

He greeted me by saying his shirt was wet. I told him we would change it in the room. He replied, "O.K."

Gestural Mode

UG Uses gestures or movements of the finger, hand, or body in an undifferentiated pattern or not in relation to a specific context.

Examples:

He wiggled his whole body when he saw his sister.

He waved his hand to say "hello," "good-bye," to summon attention to himself, and in a variety of other situations.

DG Uses gesture; consistently in a specific situation or for a given purpose (waving "bye, bye," shaking head "yes" or "no").

Examples:

He clapped his hands in praise of his achievement with the peg board.

She always raised her head and shoulders when she wanted to be picked up.

SG Child uses gestures which symbolically depict properties of objects, situations, or are analogous to words.

Examples:

She pulled on the strap, which was holding her into the chair, to let me know that she wanted to get down.

He pointed to the light in the ceiling and then to the light in the flashlight as if to say "same".

SG+ Combines several explicit gestures into a sequence.

Examples:

Through gestures and sounds, he made it clear to me that he wanted to get the top off.

Immediately she began protesting and pointing to the chair in fear that he would get there first. When I asked her if she wanted to sit in the chair, she quickly shook her head "yes" and gestured toward it.

SG → Child is involved in continuing gestural interchange, which often includes elaborated and extended gestures.

Examples:

When she tasted the sugar, she made an odd face. I could not tell if she liked or disliked it, so I asked her. She answered with a minimal kind of head shake "no". I added a cup of salt for her to taste. She did. This time her face showed clear displeasure with the taste. I asked, "You want water?" She shook her head "yes".

B. Non-Hierarchical Dimensions

1. Af AFFECT: Expresses feelings or emotions. The coding combines:

Quality -- neutral (0)
positive (+)
negative (-)

Type -- appropriate (+)
inappropriate (-)

Intensity-- passive (1)
mild or moderate (2)
extreme (3)

<u>Quality</u>	<u>Type</u>	<u>Intensity</u>	<u>Examples</u>
+	+	3	
Positive	Appropriate	Laughter, extreme joy	As I pulled the towel from his mother's face, he roared with laughter. He put his tambourine on his head, looked at us and laughed.
+	+	2	
Positive	Appropriate	Smiling, enjoyment, pleasure	He looked up at me with his excellent eye contact, smiling. He threw and chased the ball with complete independence and enjoyment.
0	+	1	
Neutral	Appropriate	Passive	She was sitting on Pat's knee having her hair brushed and accepted this easily. Her mother took her to P.T. and reported that she had not cried as on previous days with her.
-	+	2	
Negative	Appropriate	Whining, complaining, whimpering	He began to whine as he saw the nurse approach with a shining instrument in her hand. Again his mother tried to get him involved in the task, but he continued to complain and appeared to prefer her comfort.

<u>Quality</u>	<u>Type</u>	<u>Intensity</u>	<u>Examples</u>
- Negative	+ Appropriate	3 Crying, screaming, anger	She screamed as she tried to reach the doll that the other child pulled away from her. At going home time I put her in the crib, and she cried hard.
0 Neutral	- Inappropriate	1 Passive	He pulled at her hair and pants and she didn't complain. He bumped his head into a chair but did not cry.
- Negative	- Inappropriate	2 Whining, Complaining	When I gave him more juice, he unexpectedly began to frown and whimper. As I began to remove him from the chair, he started to complain, although he had indicated that he wanted to get down on the floor.
- Negative	- Inappropriate	3 Crying, screaming	Soon after his mother picked him up, he began to cry uncontrollably. After he finished his juice, he began crying, eye-rubbing, and self-stimulating body tickling.
+ Positive	- Inappropriate	2 Smiling, grinning	Sandy smiled as she watched Billy cry when his mother left. Everytime Lewis sneezed, he smiled.
+ Positive	- Inappropriate	3 Laughing	At one point someone began to choke while drinking, and Tommy began to laugh. He pushed her to the floor and then began laughing uproariously.

2. MO

GROSS MOTOR ABILITY: Evidence of large muscle movement -- either body, arms, or legs. The absence of such activity, when it is within the child's physical capacity, is indicated by circling the coding.

MO

Examples:

He moved around the table with side-stepping motions while holding onto the edge of the table with both hands.

MO

She picked up the tambourine from the table.

MO

He did not attempt to walk when placed in the ring walker.

MO

Although she often engaged in ball play, she made no attempt to push the ball which had been placed in front of her.

3. mo

FINE MOTOR ABILITY: Child displays ability to use fine motor skills -- manipulations which frequently require a pincer grasp.

Examples:

mo

She threaded five beads onto the string one at a time, requiring the teacher's help only in holding the first two beads. She did the rest independently.

mo

He carefully copied the circle on the paper with the red crayon.

mo

After picking up two small beads, she began complaining to the teacher that she couldn't pick up any more.

II. Qualifying Behaviors -- These codings can be used in combination with the behavioral dimensions when such fine-grained quantitative and qualitative analysis of the child's behavior is desired. These codings delineate all independent behaviors (IND) as either self-initiated (in) or as a variety of assertive behaviors (as, pas, pras, nas, tas). Also included are imitative behavior (*) and activities which reflect intense involvement (⇒).

A. Independent Behaviors -- Independent behaviors have been conceptualized as either primarily assertive, preferential, persistent, or self-initiated. These qualifications can be applied to all dimensions, except Affect, which is always conceived of as being self-initiated.

1. in SELF-INITIATED BEHAVIOR: The child commences activity or interaction. Behaviors not in response to others' demands, requests, or suggestions.

Examples:

in M3	She pulled the peg boat toy from the shelf and proceeded to watch the wheels as she rolled it back and forth on the floor.
in In2	He began to rub his hand on the carpet and then the tile when I placed him on the floor.
in So2 AP	She smiled when her mother entered the room.
in Co WS	Carol asked, "Where's Linda," when she returned from physical therapy.
in MO	I watched as she pulled herself to standing at the side of her crib.
in mo	Although the cereal had spilled all over the table, he carefully picked up each piece and put it back in the bowl.

2. **ASSERTIVE BEHAVIORS:** Assertive behaviors are those behaviors which indicate the child's strong-willed, persistent, or preferential action in regard to an individual, an activity, or a situation. The behaviors can be used in reference to the dimension as a whole and need not be coded at a particular level within a dimension.

- a. **as** Simple Assertive Behavior -- This is used to denote any behavior in which the child strongly exerts his own will.

Examples:

- as M The other children were using phones, so he reached across and took the phone in front of me.
- as En When we entered the bathroom, he pulled me to the tub.
- as So He reached across towards his mother as she entered the room.

- b. **pras** Preferential Behavior -- The child clearly indicates his desire to have one choice rather than the other.

Examples:

- pras So I had been holding Kim, but when her mother entered the room, Kim stretched out her arms to her mother.
- pras M When offered the toy telephone, Billy turned around and reached for the doll.
- pras MO He was crawling along the floor, and I tried to help him walk, but he lowered himself to the floor again and continued crawling.

- c. **pas** Persistent Behavior -- Despite handicapping conditions or other obstacles, the child works hard to achieve his particular objective.

Examples:

- pas mo She finally buttoned the doll's dress despite the tremor in her hands.
- pas M4 She stretched hard to reach the top of the spindle. She needed a little help from the teacher to position the hole in the disc over the spindle so that it could slide down to its base.

- d. **tas** Terminating Behavior -- The child decides or chooses to terminate a response or an activity.

Examples:

- tas M After replacing three of the four forms into the board, he threw the last form on the floor and walked to the other end of the room.
- tas So5 We had all been playing "shake-shake" when she suddenly decided to put her head on the table and ignore us.
- e. nas Rejecting Behavior -- The child rejects an activity, person, or situation.

Examples:

- nas M She refused to hold the doll offered by the teacher.
- nas So She continued to throw the sand on the floor, even though the teacher had stopped her several times during the last few minutes.

B. Imitative Behaviors

- * Responses of a child which appear to be a direct copying of either an adult (A) or a child's (C) behavior.

Examples:

- MO* C Mary then picked up a ball and threw it against the wall just as she had seen Billy just do with his ball.
- Co* A He said "book" immediately after the teacher said "book".
- MO* A She stacked one cube at a time, following the teacher's movements, until it was four cubes high.

C. Intense Involvement in or Attentiveness to an Activity

- ⇒ Responses which exhibit concentration or maintaining attention to an activity for an extended period of time. (This is not used to denote perseverative behavior, which should be annotated separately.)

Examples:

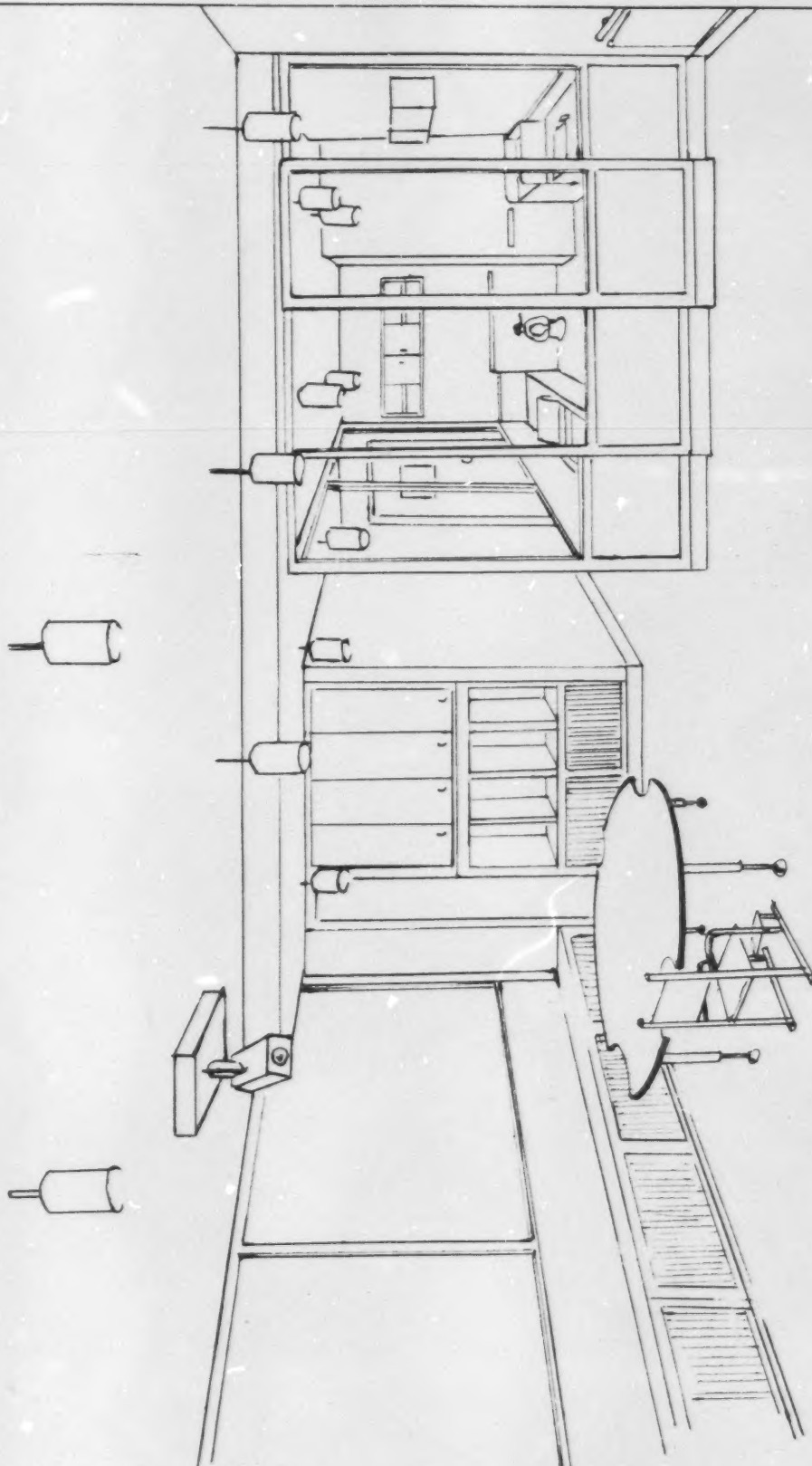
- M5 ⇒ She examined each puzzle piece and then examined the puzzle board before she replaced all the pieces correctly into the Rain Puzzle Board.
- So5 A ⇒ David and the teacher looked at the pictures in the book together for a long time. The teacher would point to each picture. David would then look up at her and wait for her to say something and then he tried to repeat what she said. When he could, he immediately offered to label a picture before examining it carefully and then waited for a response from his teacher before turning the page.

III. Symptomatic Behaviors -- Repetitive behaviors which tend to interfere with the child's expected functioning are recorded on a separate sheet during the child's stay in the program. Each behavior is assigned a lower case letter and is coded as a symptomatic behavior whenever it appears in a log record, rather than in the dimension to which it relates.

Examples:

- | | |
|--------|--|
| Symp a | Makes duck-like sounds (e.g., when I entered the room, I could hear Robbie making his duck-like noises). |
| Symp b | Fear of loud bells (e.g., as usual, she began to scream when the telephone rang). |
| Symp c | When annoyed, began to bang his head against the wall. Although I tried to have him indicate what was wrong, he continued to bang his head against the wall instead. |

Figure 1
Layout of the Infant Room



Item 1

SAMPLE DAILY SCHEDULE

8:00 - 9:00	Medical Rounds/Dressing/Breakfast
9:00 - 9:30	Occupational Therapy
9:30 -10:30	INFANT SCHOOL
10:30 -11:00	Physical Therapy
11:00 -11:30	INFANT SCHOOL
11:30 - 2:00	Lunch/Nap
2:00 - 2:30	Speech Therapy
2:30 - 4:00	INFANT SCHOOL
4:00 - 7:00	Parent Visits: Bath/Dinner

Item 2

I. S. Goals week of 5/28/75

Child 00

1. Independent gross motor activity such as climbing, sliding down ramp, etc. because of emerging developmental stage.
2. Beginning development of spoken language. Since she "talks" in gestures, we will start by translating her gestures into appropriate simple words. We will not stress imitation of sounds or lip movements, but rather try for a natural "flow" of language. We will also use finger, singing, and motor imitation games to encourage this.
3. Increased awareness of her left hand and side. We will use bracelets, sit on her left side and use tactual clues to remind her to use left hand as assist. We will offer a variety of activities for which she needs two hands. We will assist her by balancing cubes for stacking, etc. to provide balance of success with motivation to overcome frustration.
4. Rotation of wrist. We will offer dumping and pouring activities to encourage this.
5. Pushing doll carriage or another child's wheelchair, as extension of physical therapy goals.

I. S. Goals week of 6/11/75

Child 00

1. Increased concentration span and focus. We will insist (and assist if necessary) upon completion of one task or activity before moving to another. We will use the word "finish" and give visual and gestural clues such as taking smock off or returning materials to container. We will begin this with five or ten minute tutorial sessions, removed from the group, and extend the time as we pick up clues that she is ready.
2. Beginning size discrimination. We will use nesting toys, starting with the largest and smallest only and introducing a third one if she seems ready. We will also use containers, sponges, etc. of exaggerated size differences, for play with more free flowing materials.
3. Continue all previous goals. (Long range physical therapy, rotation of wrists.)
4. Increased awareness of her own body in space, specifically in relation to going under because of evidence of difficulty with this.

I. S. Goals week of 7/9/75

Child 00

1. Continue awareness of samenesses and differences. We will continue to use sorting activities including two colors, which we were unable to introduce previous week.
2. Continue all previous goals, because of progress noted and need to stabilize existing strengths.
3. Use of involved side in gross motor activities (pushing large ball, closing doors, etc.) as extension of physical therapy goals.
4. Increased awareness of symbolizations, using three dimensional representational objects with pictures. She has recently incorporated babbling into some of these activities, and we hope to encourage this at the same time.
5. Extend independence to turning water and light switches off and on. This will also extend awareness of cause and effect.
6. Interaction with a peer. We will provide parallel play with child QQ.

I. S. Goals week of 4/9/75

Child PP

1. Basic relatedness to an adult through close and frequent physical contact combined with eye contact in rocking, lap-play games, tickling in the crib, etc.
2. Lessening of resistance and upset during transitions. We will ease transfer by supplying a favorite toy for focus during change.
3. Decrease in head banging. We will hold him firmly when he begins this.
4. Imitation of babbling sounds and simple words because of recent evidence of ability.
5. Self-help in feeding. We will encourage finger feeding and holding his own bottle to begin with.
6. Reciprocal independent crawling, knee-standing, and knee-walking, as extension of physical therapy goals.
7. Independent containment activities. We will place boxes and other containers filled with assorted objects in his path and observe spontaneous use from a distance.
8. Tactual sensory stimulation (water play, finger paint, soap suds, etc.) because of enjoyment of this and to encourage focus.
9. We will also offer a variety of higher materials such as books, cylinder-pegs, dolls, and mirror in order to observe responses, because of some evidence of masking of higher functional abilities.

Table 1
Demographic Data on 40 Children

Child*	Sex	CA	MA	IQ	Child's Ethnicity	Occupation of Head of Household	Socioeconomic Status**	Language in Home
A	M	30	25	83	White American	Cleans aircraft	Low	Italian, English
B	F	33	5	15	Hispanic	-	Public Assist.	Spanish
C	M	36	24	67+	White American	Tech. Supervisor	Middle	English
D	F	29	3	11	Hispanic	Hosp. Attendant	Low	Spanish
E	F	24	4	17	White American	Entertainer	Middle	English
F	M	35	29	83+	White American	Aircraft engineer	Middle	English
G	M	34	24	70+	Hispanic	Printer	Middle	Spanish
H	M	26	6	17	Black American	Watchmaker	Middle	English
I	M	32	6	19	White American	Clerk	Middle	English
J	F	23	14	61+	White American	Butcher	Low	English
K	M	35	28	80+	Black American	-	Public Assist.	Spanish, English
L	M	25	7	29	Black American	Trainee	Public Assist.	English
M	M	32	21	66+	Hispanic	-	Public Assist.	English
N	F	26	5	19	White American	Attorney	High	English
O	F	30	21	69+	Chinese	Secretary	Middle	Chinese
P	M	19	11	58+	White American	Salesman	Middle	English
Q	M	35	10	29	Hispanic	-	Public Assist.	English
R	M	36	6	16	Hispanic	Salesman	Low	Spanish
S	F	21	4	19	White American	Cargo Handler	Middle	Spanish
T	M	24	18	75+	Hispanic	Student	Public Assist.	English
U	F	39	9	23	White American	Grad. Student	High	Spanish
V	F	25	11	44	Hispanic	Bldg. Supt.	Middle	English
W	F	35	14	40	White American	Int'l. Banker	High	Spanish
X	M	30	13	43	Black American	-	Public Assist.	English
Y	F	33	5	15	Black American	Construction Wkr.	Middle	English
Z	F	33	12	36	White American	Accountant	Middle	English

AA	F	33	11	33	White American	Carpenter	Middle	English
BB	F	29	12	41	White American	Salesman	Middle	Hebrew, English
CC	F	33	30	91	Hispanic	-	Public Asst.	Spanish
DD	M	26	9	37	Hispanic	Film Developer	Low	Spanish, English
EE	M	26	7	27	Hispanic	Transitman	Middle	English
FF	F	29	27	93	Hispanic	Student	Middle	Spanish, English
GG	M	37	5	14	Hispanic	Patrolman	Middle	Spanish, English
HH	F	35	7	20	Black American	-	Public Asst.	English
II	M	31	10	30	Black American	Alde	Low	English
JJ	M	22	3	14	White American	Carpenter	Middle	English
KK	M	36	6	17	White American	Truck Driver	Middle	English
LL	M	31	6	19	Black American	Recreation Dir.	Middle	English
MM	M	40	5	13	White American	-	Public Asst.	English
NN	M	31	22	67	Hispanic	Homemaker	Low	Spanish

*Letters are assigned to each child with reference to sequence of entry into the program

**Langner & Michael, 1963

Table 2

Expanded Medical Diagnosis (N = 40)

<u>Child</u>	<u>Medical Diagnosis</u>	<u>Additional Comments</u>
A	Cerebral Palsy (CP)	Congenital, mild right hemiparesis
B	CP	Congenital, post-rubella, spastic paresis
C	CP	Congenital, brain damage, mild spasticity in all four extremities, language disorder
D	CP	Congenital, quadriplegia, overall retardation
E	CP	Acquired, post-trauma (car accident), left hemiparesis, right subdural hematoma, left cortical blindness
F	CP	Congenital (associated with prematurity), spastic diplegia
G	CP	Congenital, post-rubella, spastic diplegia, bi-lateral hearing loss
H	CP	Congenital, hypotonia, general retardation
I	Brain Damage	Congenital, emotional disorder, delayed development
J	Brain Damage	Congenital, hypotonia, delayed development
K	CP	Congenital, associated with prematurity (one of twins), left hemiparesis
L	CP	Congenital, mixed spastic and athetoid, overall retardation
M	Spina Bifida	Congenital, paraplegia, hydrocephalus (shunted), lumbar 2-3 lesion
N	CP	Acquired, hydrocephalus, brain cyst, normal to 3 months
O	CP	Acquired, post-meningitis (at 4 months), spastic left hemiparesis
P	Hydrocephalus	Congenital, shunted
Q	CP	Congenital (associated with prematurity), spastic quadriplegia
R	CP	Congenital, mixed spastic and athetoid
S	CP	Congenital (associated with prematurity), microcephaly, possible cortical blindness and/or deafness
T	CP	Congenital, mild spastic diplegia
U	Delayed Development	Congenital psychomotor retardation
V	CP	Congenital, spastic diplegia, microcephaly, delayed development
W	Brain Damage	Congenital, delayed development
X	CP	Congenital, spastic diplegia
Y	Cri du Chat	Congenital, hypotonia
Z	CP	Acquired, mild spastic hemiparesis
AA	CP	Congenital
BB	CP	Congenital, mixed athetoid and spastic
CC	Spina Bifida	Congenital, paraplegia
DD	CP	Congenital (associated with prematurity), left hemiparesis

EE	Hydrocephalus	Congenital, shunted, left spastic hemiplegia, hypotonia
FF	CP	Congenital, spastic diplegia
GG	Spina Bifida	Congenital, paraplegia, partial blindness, hydrocephalus arrested
HH	CP	Acquired, spastic, left hemiparesis
II	CP	Congenital, spastic, quadriplegia
JJ	CP	Perinatal, spastic quadriplegia, visually impaired
KK	CP	Related to neonatal seizures, spastic diplegia, possible hearing impairment
LL	Delayed Development	Congenital, congenital heart defect, visual impairment
MM	CP	Acquired, tonic and athetoid, diparesis, seizures (etiology unknown), visual impairment
NN	CP	Congenital, left spastic hemiplegia, delayed motor development

Table 3

Medical Diagnosis and Joint Clinical Judgments as to
Degree of Disability and Delay Upon Admission (N = 40)

Child	Medical Diagnosis*	Motor Dev.	Lang. Dev.	Intel. Dev.	Social Dev.	Affect. Dev.	Sum Delay Score
A	CP**	3	3	4	3	3	16
B	CP**	1	1	1	2	2	7
C	CP**	2	2	3	4	3	14
D	CP**	1	1	1	2	3	8
E	CP***	3	1	1	1	1	7
F	CP**	4	4	3	4	3	17
G	CP**	1	1	3	3	3	11
H	CP**	1	1	1	1	1	5
I	Brain Damage	3	1	2	2	1	9
J	Brain Damage	3	3	3	2	2	13
K	CP**	3	2	3	3	3	14
L	CP**	2	1	1	1	1	6
M	Spina Bifida	2	2	3	3	3	13
N	CP***	2	1	1	2	1	7
O	CP***	2	2	3	4	3	14
P	Hydrocephalus	3	3	2	4	3	15
Q	CP**	1	1	2	3	3	10
R	CP**	1	1	2	3	3	10
S	CP**	1	1	1	1	1	5
T	CP**	2	3	4	4	4	17
U	Delayed Devel.	1	1	1	1	1	5
V	CP**	2	1	2	4	3	12
W	Brain Damage	2	2	2	2	2	10
X	CP**	2	1	2	4	4	13
Y	Cri du Chat	2	1	1	1	1	6
Z	CP***	3	1	2	3	3	12
AA	CP**	1	1	1	2	1	6
BB	CP**	2	1	2	3	2	10
CC	Spina Bifida	2	4	4	3	3	16
DD	CP**	2	1	1	2	2	8
EE	Hydrocephalus	1	1	1	1	1	5
FF	CP**	3	4	4	4	4	19
GG	Spina Bifida	3	1	1	1	1	7
HH	CP***	2	1	1	2	1	7
II	CP**	2	1	2	3	2	10
JJ	CP***	1	1	2	2	2	8
KK	CP***	2	2	1	1	1	7
LL	Delayed Devel.	2	1	1	1	1	6
MM	CP***	2	1	1	1	1	6
NN	CP**	2	3	4	4	3	16

- * See Table 2, Appendix IV for expanded medical diagnosis.
 ** Congenital cerebral palsy
 *** Acquired cerebral palsy

Key

- 1 = Severe delay
 2 = Moderate delay
 3 = Mild delay
 4 = Normal development

Item 1

Sample Log -- Child BB

After others left, I brought over bowl, box of cereal, packets of sugar and small potato masher on a tray. She seemed to recognize the cereal immediately. Tried to open box. Couldn't. I started to tear and pointed to it. BB finished the tearing independently. When it was opened, she held it up to her face and looked inside. Put hand in, took out a piece, and ate it. I demonstrated mashing cereal. Then I gave her the bowl and the masher. She rejected this physically and by making loud vowel protests. I showed her a sugar packet by shaking it. She took and attempted to open. Could not. I assisted as I had with box. I dumped some and encouraged her to complete the dumping. She showed no interest in dumping. Here I lose the sequence, but somehow I eventually reintroduced the masher. After watching me, she tried to adjust her grasp. At first she vocally protested at my interference, but the noise and the action of the mashing distracted her, and she began to mash independently with well coordinated movement (for her disability). She used her free hand to hold the bowl as she mashed. I gave her a spoon. She used it to eat a little. She was not really enthralled with the taste, so I brought a doll to feed. She had trouble coordinating the reach to the doll's mouth and in keeping the cereal on the spoon as she did. Fed herself a little more. Still not much interest in that. I asked her verbally to feed me. Did not. I demonstrated by taking her hand in mine and placing the spoon in my mouth. She then fed herself one spoonful.

Later she became intrigued with ribbon in doll's hair. Removed it. Held it to her own head in an effort to put it on. I made her a pony tail with it and brought a mirror for her to see. Looked in mirror. I tried to get her to put the doll away in a box. BB took it out again and hugged. Then she began removing all the doll play objects from the box and handing them to me. As she did so, I verbally labeled them for her. When I asked her, "Where does this go?" (about hat), she draped it over the doll's head. Also brought a sock to the foot. She also tried to put the tie-fastened shirt on the doll's head. This seemed reasonable since it had strings like the hat. Together we put everything back into the box. She moved to take out again, so I picked up the box lid and got her focused on putting that on. She could not manage that completely independently, but understood. I helped position it for her.

I pulled out her chair and told her to get down. She wiggled in her seat. Then I discovered that she was strapped in by a strap hidden by her dress. I unfastened. She slid down as I held her hands.

She became interested in the stack of boxes that DD was knocking over. BB had some brief interchange with him (vocal and eye contact). She also attempted to restack the boxes. DD suddenly hit her very hard in the face. She stopped her activity and looked at him with a very strong facial expression that was a mixture of anger and hurt. Clearly showed she did not like that.

At this point I had to phone P.T., speak with BB's mother in hall, etc., and lost the sequence. I do know that Mr. and Mrs. BB joined us for snack and that BB held together much better than she usually does when both parents are present.

At snack she poured her own juice with a little help from me in lifting and positioning.

After snack mother and father took her for a walk. BB walked out of I.R. independently on rollator.

Table 4a

Rank Correlations:
Intercoder Reliability Data (Children A - J)

	<u>Range of r</u>	<u>Mean r</u>	<u>SD</u>
Materials (M)	.486 - .963	.828	.135
Social (So)	.360 - 1.000	.829	.186
Language (Lg)	.509 - 1.000	.858	.167
Affect (Af)	.779 - 1.000	.933	.083
Across all hierarchical dimensions	.687 - 1.000	.946	.045
IND across all dimensions	.819 - .976	.918	.039

Table 4b

Percent Agreement:¹
Intercoder Reliability Data (Children K - T)

	<u>No. of Options</u>	<u>Range</u>	<u>Mean</u>	<u>SD</u>
Materials (M)	8	54 - 79	69.5	8.721
Social (So)	6	59 - 91	74.7	9.464
Language (Lg)	13	0 - 100	78.8	28.921
Environment (En)	4	0 - 100	50.9	34.806
Means across Hierarchical Dimensions	-	52 - 91	68.5	11.326
Affect (Af)	10	83 - 100	93.5	3.472
Gross Motor (MO)	2	72 - 95	81.7	6.913
Fine Motor (mo)	2	44 - 100	74.1	20.824
Sensory Responsiveness (Sr)	3	0 - 100	66.7	30.070
Means across Non-hierarchical Dimensions	-	54 - 95	79.3	12.202
IND Materials	6	36 - 100	73.2	18.195
IND Social	6	40 - 100	68.2	14.733
IND Language	6	0 - 90	62.4	35.478
IND Environment	6	0 - 78	45.9	27.388
IND Gross Motor	6	44 - 92	71.9	17.285
IND Fine Motor	6	0 - 100	45.7	43.924
IND Sensory Responsiveness	6	0 - 100	83.9	33.381
Means across IND Dimensions	-	45 - 80	64.5	10.886

¹ Percent agreement between Coder X and Coder Y = $\frac{\text{Behaviors Coded by X}}{\text{Behaviors Coded by X} + \text{Behaviors Coded also by Y}}$

$\frac{\text{Behaviors Coded by X} + \text{Behaviors Coded by Y}}{\text{Behaviors Coded by X} + \text{Behaviors Coded by Y}}$

-2

(Refinement of reliability procedure used for Children A - J).

Table 4c

Percent Agreement:¹
Intercoder Reliability Data (Children U - NN)

	<u>No. of Options</u>	<u>Range</u>	<u>Mean</u>	<u>SD</u>
Hierarchical Dimensions:				
Interaction with Materials (M)	7	61 - 90	79.25	7.54
Awareness of the Environment (En)	6	51 - 94	73.55	11.81
Social Responsiveness (So)	5	61 - 96	78.00	9.74
Expressive Communication (Co)	13	57 - 100	81.15	13.31
Non-Hierarchical Dimensions:				
Affect (Af)	10	73 - 100	86.55	8.61
Gross Motor (MO)	2	67 - 93	82.60	7.94
Fine Motor (mo)	2	0 - 100	78.55	32.58
Total Independent Behavior (IND)	6	50 - 84	64.30	10.12
IND M	6	12 - 91	61.75	20.96
IND En	6	0 - 100	56.90	19.82
IND So	6	0 - 100	89.50	20.53
IND Co	6	0 - 100	89.15	32.05
IND MO	6	33 - 100	65.20	18.89
IND mo	6	0 - 100	66.68	47.14

¹Percent agreement between Coder X and Coder Y = $\frac{\text{Behaviors Coded by X Coded also by Y}}{\text{Behaviors Coded by X} + \text{Behaviors Coded by Y}}$

Behaviors Coded + Behaviors Coded
by X by Y

2

Item 2

Sample Coded Log -- Child BB

0 [After others left, I brought over bowl, box of cereal, packets of sugar

and small potato masher on a tray. She seemed to recognize the cereal immediately.

pasMO, M4

Tried to open box. Couldn't. I started to tear and pointed to it. BB finished

M5, MO

the tearing independently. When it was opened, she held it up to her face and

En3

looked inside. Put hand in, took out a piece, and ate it. I demonstrated

NasM

mashing cereal. Then I gave her the bowl and the masher. She rejected this

MO

inCOUV

physically and by making loud vowel protests. [2] I showed her a sugar packet by

pasmo, M4

shaking it. She took and attempted to open. Could not. I assisted as I had

with box. I dumped some and encouraged her to complete the dumping. She

M1

showed no interest in dumping. [3] Here I lose the sequence, but somehow I

SO2A

eventually reintroduced the masher. After watching me, she tried to imitate,

MO*A, M4*A

but grasped the handle of the masher in a backhanded manner. I tried to adjust

NasSO, inCOUV

her grasp. At first she vocally protested at my interference, but the noise

and the action of the mashing distracted her and she began to mash independently

M5, pasMO

with well coordinated movement (for her disability). She used her free hand to

inEn4, cont.(MO)

hold the bowl, as she mashed. [4] I gave her a spoon. She used it to eat a little.

M5, MO

En2

She was not really enthralled with the taste, [5] so I brought a doll to feed. She

M4, MO, En4

had trouble coordinating the reach to the doll's mouth and in keeping the cereal

M5, MO

on the spoon as she did. Fed herself a little more. Still not much interest

in that. I asked her, verbally, to feed me. Did not. I demonstrated by
taking her hand in mine and placing the spoon in my mouth. She then fed
herself one spoonful.]

⑥ [Later she became intrigued with ribbon in doll's hair. Removed it.

Held it to her own head, in an effort to put it on.] I made her a pony tail

with it and brought a mirror for her to see. Looked in mirror.] I tried to

get her to put the doll away in a box. BB took it out again and hugged.

Then she began removing all the doll play objects from the box and handing

them to me. As she did so, I verbally labeled them for her. When I asked

her, "Where does this go?" (about hat), she draped it over the doll's head.

Also brought a sock to the foot. She also tried to put the tie-fastened

shirt on the doll's head. This seemed reasonable since it had strings like

the hat. Together, we put everything back into the box. She moved to take

out again, so I picked up the box lid and got her focused on putting that on.

She could not manage that completely independently, but understood. I

helped position it for her.]

9 [I pulled out her chair and told her to get down. She wiggled in her
seat. Then I discovered that she was strapped in by a strap hidden by her

dress. I unfastened. She slid down as I held her hands.]

⑩ [^{M3} She became interested in the stack of boxes that DD was knocking over. ^{En2}

^{SO3C} BB had some brief interchange with him (vocal and eye contact). She also ^{in CO UV}

^{M4, MO} attempted to restack the boxes. DD suddenly hit her very hard in the face.

She stopped her activity and looked at him with a very strong facial expression

^{AF 0-1} that was a mixture of anger and hurt. Clearly showed she did not like that.]

At this point, I had to phone P.T. speak with BB's mother in hall,

etc. and lost the sequence. ⑪ [I do know that Mr. and Mrs. BB joined us for

^{AF 0+1} snack and that BB held together much better than she usually does when both ^{SO2AP} parents are present.

^{M4, MO} At snack, she poured her own juice with a little help from me in lifting and positioning.]

⑫ [After snack, mother and father took her for a walk. BB walked out of ^{MO} I.R. independently on rollator.]

Item 3
SAMPLE TRANSFER SHEET - Child BB

Item 3

Activity	LEVEL ANALYSIS	M	En	So	Co	At	MO	MO	Annotations
1. Looking Tries to open cereal box		4					pas	✓	✓ pulling open box
Opened after teacher assisted	24 mos	5					✓	✓	looked inside box ✓ removed piece of cereal refused food mother physically
2. Attempts to open sugar package Did not want to dump sugar out		4			in UV		pas	✓	
3. Tries to use food masher		4		2A			pas	✓	imitates C.B. vocal protests, rejects assistance
Uses food masher	24 mos	5	in 4	Nas	in UV		pas	✓	uses free hand to hold bowl
4. Ate some cereal with spoon	18 mos	5					✓	✓	reacted negatively to taste of cereal
5. Had difficulty in bringing spoon to doll's mouth Fed herself more	18 mos	5					✓	✓	did not respond to C.B.'s request for some cereal
6. Doll Removed ribbon from doll's head	18 mos	in 5	in 3				in	✓	looked at ribbon in doll's hair
7. Looked at self in mirror			in 4				in	✓	held ribbon up to own head

SAMPLE TRANSFER SHEET - CHILD BB

ACTIVITY	LEVEL ANALYSIS	M	Eh	So	Co	At	MO	MO	Annotations
8. Wanted to keep doll Hugged doll Removed all doll play objects from box	pram 2 in 6 in 5		4	in 3A 4A			in in		handed objects from box to C.G. put her on doll's head in response to "where does this go?" dropped sock on foot tried putting shirt on doll's head put all objects back in box with assistance of C.G.
9. Getting off chair: tried to remove object from box again Could not manage putting top on box	pram 4		3	5A			✓		wiggled in seat slid off after strap was removed
10. Boxes: watched them being knocked down by BB Attempts to restack boxes	3 4		2	5A 3C in W			✓		some vocal contact
11. With Parents at Snake	4			3Ap		0-1 0+1	✓		Did not respond when hit Calm when held by parents poured some juice with help walked in hallway
12. With roller							✓		

Item 4

Sample Tally Sheet -- Interaction with Materials

	1 # of Episodes 12				2 # of Episodes				3 # of Episodes			
	ABS.	%	$\bar{x}$	wt $\bar{x}$	ABS.	%	$\bar{x}$	wt $\bar{x}$	ABS.	%	$\bar{x}$	wt $\bar{x}$
as	2	67	.17									
pres	0	0	0									
pas	0	0	0									
tas	0	0	0									
nas	1	33	.08									
AS	3	50	.25									
in	3	50	.25									
IND	6		.50									
⇒	0		0									
*	1		.08									
1 st	1	6	.08									
2 nd	1	6	.08	.08								
3 rd	2	12	.17	.34								
4 th	7	41	.58	1.74								
5 th	5	29	.42	1.68								
6 th	1	6	.08	.40								
7 th	0	0	0	0								
TOTAL	17		1.41	4.24								
PASSIVE	1	6	.08									
ACTIVE	16	94	1.33									

Item 5

Sample Summary Sheet

	1 # of Episodes — 12				2 # of Episodes —				3 # of Episodes —			
	Abs	%	$\bar{X}$	Wt. $\bar{X}$	Abs	%	$\bar{X}$	Wt. $\bar{X}$	Abs	%	$\bar{X}$	Wt. $\bar{X}$
AS	8	36	.67	/				/				/
In	14	64	1.17	/				/				/
IND	22	/	1.83	/		/		/		/		/
⇒	0	/	.00	/		/		/		/		/
*	2	/	.17	/		/		/		/		/
M	17	26	1.41	4.24								
En	10	17	.83	1.82								
So	8	13	.67	1.23								
Co	3	5	.25	.25								
Af	2	3	.17	/				/				/
Mo	18	30	1.50	/				/				/
mo	2	3	.17	/				/				/
TOTAL	60	/	5.00	7.54		/		/		/		/
Passive	56	93	4.67	/				/				/
Active	4	7	.33	/				/				/
Hier.	38	63	3.17	7.54								
Non-Hier.	22	37	1.83	/				/				/

Table 5

Rank Test for Correlated Data Between Pre Scores Across Hierarchical Dimensions
and Between Post Scores Across Hierarchical Dimensions (N=20)

	<u>M</u>		<u>SC</u>		<u>Lg</u>		<u>En</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
Pre r t			.60		.69		.77	
Post r t			3.20**		4.04**		5.07**	
				.51		.52		.41
				2.52*		2.62*		1.93
Pre r t			.75		.36			
Post r t			4.81**		1.64			
						.69		.45
						4.08**		2.16*
Pre r t					.55			
Post r t					2.83*			
						.40		
						1.86		

* Significant at .05 level.

** Significant at .01 level.

Table 6

Correlations Between Two Independent Ranks
of Child Functioning: Teacher and System Data (N = 20)
Showing Problem with
Awareness of Environment Dimension

		<u>Pre</u>	<u>Post</u>
M:			
	r	.819	.758
	t	6.06**	4.93**
So:			
	r	.662	.800
	t	3.74**	5.65**
Lg:			
	r	.816	.914
	t	5.99**	9.55**
En:			
	r	.689	.366
	t	4.03**	1.67

** Significant at .01 level.

Table 1a

Rank Test for Correlated Data Between
Pre - Post Scores on Videotape (N = 19)

<u>Total Weighted $\bar{x}$</u>	<u>r</u>	<u>t</u>
M	.661	3.63**
En	.656	3.58**
So	.605	3.13**
Lg	.708	4.13***

** $p < .01$

*** $p < .001$

Table 1b

Rank Test for Correlated Data
Between Videotapes and Logs (N = 19)

	<u>r</u>	<u>t</u>
<u>Video M to Log M:</u>		
Pre	.828	6.09***
Post	.547	2.69*
<u>Video En to Log En:</u>		
Pre	.445	2.05
Post	.353	1.56
<u>Video So to Log So:</u>		
Pre	.632	3.36**
Post	.500	2.38*
<u>Video Lg to Log Lg:</u>		
Pre	.631	3.35**
Post	.863	7.04

* $p < .05$
 ** $p < .01$
 *** $p < .001$

Table 1c

Task Analysis of M3 Level of Interaction with Materials (M)
Applied to Videotapes (N = 19)

		<u>Task Analysis Pre</u>		<u>Task Analysis Post</u>	
		<u>r</u>	<u>t</u>	<u>r</u>	<u>t</u>
<u>Total Weighted $\bar{x}$ M:</u>					
	Pre	.817	5.84***		
	Post			.912	9.17***
<u>MA:</u>					
	Pre	.926	10.11***		
	Post			.855	6.80***
<u>CA:</u>					
	Pre	.444	2.04NS		
	Post			.323	1.41NS

*** $p < .001$

NS = Not significant

Table 1d

Correlation Coefficients (Pearson)
between Videotapes and Logs (N = 39)

<u>Video M to Log M:</u>	<u>r</u>
Pre	.65***
Post	.49***
<u>Video En to Log En:</u>	
Pre	.53***
Post	.49***
<u>Video So to Log So:</u>	
Pre	.50***
Post	.51***
<u>Video Lg to Log Lg:</u>	
Pre	.83***
Post	.76***

*** p < .001

Table 2

Partial Correlations Used to Show Relationship
Between Dimensions -- Log Data (N = 40)

<u>Variables Correlated</u>	<u>Variable Removed</u>	<u>pre</u>	<u>post</u>
Materials and Social	Communication	.24	.51**
Materials and Communication	Social	.47**	.08
Social and Communication	Materials	.32*	.47**
Materials and Social	Mental Age	.09	.32*
Materials and Communication	Mental Age	.05	-.27
Social and Communication	Mental Age	.13	.01
Mental Age and Materials	Chronological Age	.75**	.50**
Social and Communication	Chronological Age	.50**	.50**

* $p < .05$

** $p < .01$

Table 3

Age Levels in Months for Expressive Communication

<u>Child</u>	<u>Age Levels from Speech & Hearing</u>		<u>Age levels from Infant Research</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
U	6	6	6	6
V	12	18	12	18
W	9	9	10	16
X	6	NA*	6	12
Y	4	NA*	6	6
Z	9	12	7	12
AA	15	18	9	18
BB	9	12	12	12
CC	34**	21	30	36
DD	12	12	12	12

*Not available

**Spanish only

Item 1

Coding for Demographic Variables

<u>Variable</u>	<u>Code</u>
Sex	1 = Male 2 = Female
Ethnicity (child's)	1 = White 2 = Black 3 = Hispanic 4 = Other 5 = Unknown
Religion (child's)	1 = Catholic 2 = Protestant 3 = Jewish 4 = Other 9 = Unknown
Age at Admission	(in months)
Age at Discharge	(in months)
Elapsed Time in Program	(in weeks)
MA on Admission	(in months)
IQ on Admission	
Age of Father	(in years)
Age of Mother	(in years)
Marital Status: intact family	1 = Yes 2 = No
SES	1 = Public Assistance 2 = Low 3 = Middle 4 = High
Occupation of Head of Household	0 = Unemployed 1 = Blue Collar Low 2 = Blue Collar Middle 3 = Blue Collar High 4 = White Collar Low 5 = White Collar Middle 6 = White Collar High 9 = Unknown

<u>Variable</u>	<u>Code</u>
Education of Head of Household	1 = Some grammar school 2 = Grammar school graduate 3 = Some high school 4 = High school graduate 5 = Some college 6 = College graduate
Language Spoken in Home	1 = English 2 = Spanish 3 = Other
Number of Living Sibs	
Number of Disabled Living Sibs	
Medical Diagnosis	1 = Cerebral Palsy 2 = Brain Damage 3 = Spina Bifida, No Hydrocephalus 4 = Spina Bifida with Hydrocephalus 5 = Hydrocephalus 6 = Delayed development 7 = Limb defects 8 = Post-Rubella 9 = Other
Age at Diagnosis (If congenital or age at which disability acquired)	(in months)
Type of Disability	1 = Congenital 2 = Acquired
Etiology	1 = Prenatal 2 = At birth 3 = Prematurity 4 = Associated with intoxication (Heroin, lead poisoning, toxemia) 5 = Postnatal trauma 6 = Post natal infection 7 = Rubella 8 = Other 9 = Unknown
Sensory Impairment	1 = None 2 = Hearing impaired 3 = Deaf 4 = Visually impaired 5 = Blind 6 = Combined

<u>Variable</u>	<u>Code</u>
Motor Dysfunction	1 = None 2 = Hypotonic 3 = Ataxic 4 = Athetoid 5 = Spastic 6 = Mixed 7 = Flaccid 8 = Other
Location of Dysfunction	0 = None 1 = Mono 2 = Di 3 = Hemi 4 = Para 5 = Tri 6 = Quad 7 = Upper extremity amputee 8 = Lower extremity amputee
Degree of Dysfunction	0 = None 1 = Paretic 2 = Plegic 3 = Amputee
Severity of Motor Dysfunction	0 = None 1 = Severe 2 = Moderate 3 = Mild
Seizures while on Program	1 = No 2 = Yes
Medication while on Program	1 = None 2 = Some 3 = Highly
<u>Clinical Judgments</u>	
Motor Development	1 = Severe 2 = Moderate 3 = Mild 4 = Normal
Language Development	1 = Severe 2 = Moderate 3 = Mild 4 = Normal

<u>Variable</u>	<u>Code</u>
Intellectual Development	1 = Severe 2 = Moderate 3 = Mild 4 = Normal
Social Development	1 = Severe 2 = Moderate 3 = Mild 4 = Normal
Affective Development	1 = Severe 2 = Moderate 3 = Mild 4 = Normal
Sum Delay Score	Sum of Clinical Judgments

Table 4

Intercorrelations: MA, IQ, and
Clinical Judgments (N = 40)

	<u>MA</u>	<u>IQ</u>	<u>Motor</u>	<u>Language</u>	<u>Intel.</u>	<u>Social</u>	<u>Affect</u>	<u>Sum Delay</u>
MA	-	.97**	.36*	.77**	.88**	.70**	.68**	.85**
IQ		-	.42**	.83**	.91**	.74**	.72**	.90**
Motor			-	.49**	.36*	NS	NS	.51**
Language				-	.79**	.54**	.54**	.82**
Intell.					-	.77**	.78**	.93**
Social						-	.89**	.89**
Affect							-	.87**
Sum Delay								-

* $p < .05$

** $p < .01$

Table 5

Correlations between Joint Clinical Judgment
and Log Pre and Post Scores (N = 40)

	<u>Motor</u>	<u>Language</u>	<u>Intell.</u>	<u>Social</u>	<u>Affect</u>	<u>Sum Delay</u>
<u>M</u>						
Pre	.37*	.60**	.70**	.69**	.69**	.76**
Post	.34*	-	.49**	.44**	.43**	.50**
<u>En</u>						
Pre	-	-	-	-	-	-
Post	-	-	-	-	-	-
<u>So</u>						
Pre	-	.36*	.48**	.61**	.59**	.54**
Post	-	.41**	.64**	.73**	.73**	.69**
<u>Co</u>						
Pre	.40**	.78**	.72**	.60**	.57**	.75**
Post	.41**	.78**	.67**	.61**	.51**	.73**
<u>Af</u>						
Pre	-.48**	-.39**	-	-	-	-
Post	-.44**	-.34*	-	-	-	-
<u>MO</u>						
Pre	-	-	-	-	-	-
Post	-	-	-	-	-	-
<u>mo</u>						
Pre	-	.41**	.53**	.53**	.59**	.56**
Post	.36*	.35*	.58**	.48**	.50**	.57**

* $p < .05$ ** $p < .01$

Table 6

Log Data: Pre and Post Means and
Standard Deviations for Modifiers (N = 40)

	<u>Low</u>		<u>Middle</u>		<u>High</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
<u>AS</u>						
$\bar{x}$	0.26	0.33	0.53	0.63	0.52	0.58
SD	0.12	0.14	0.22	0.23	0.22	0.23
<u>in</u>						
$\bar{x}$	0.51	0.85	0.79	1.31	1.09	1.84
SD	0.38	0.58	0.42	0.56	0.38	0.75
<u>IND</u>						
$\bar{x}$	0.77	1.17	1.39	1.94	1.50	2.42
SD	0.43	0.68	0.43	0.62	0.52	0.75
$\Rightarrow$						
$\bar{x}$	0.08	0.12	0.08	0.15	0.15	0.14
SD	0.11	0.12	0.07	0.18	0.14	0.09
<u>*</u>						
$\bar{x}$	0.06	0.07	0.20	0.11	0.12	0.16
SD	0.08	0.08	0.16	0.06	0.09	0.07
<u>Passive</u>						
$\bar{x}$	0.46	0.35	0.15	0.14	0.11	0.04
SD	0.40	0.25	0.17	0.13	0.16	0.07
<u>Active</u>						
$\bar{x}$	2.79	3.38	3.96	4.70	4.12	5.16
SD	0.92	0.88	0.89	1.13	0.86	0.96

Table 7

Pre and Post Means and
Standard Deviations for Subgroups

	<u>Low (N = 19)</u>		<u>Middle (N = 11)</u>		<u>High (N = 10)</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
<u>M:</u>						
$\bar{x}$	1.06	1.66	2.48	3.28	3.14	2.61
SD	0.50	0.76	1.11	1.24	1.21	0.86
<u>En:</u>						
$\bar{x}$	0.49	0.57	0.69	0.86	0.70	0.90
SD	0.52	0.47	0.55	0.68	0.68	0.92
<u>So:</u>						
$\bar{x}$	0.89	1.10	1.47	2.41	1.75	2.79
SD	0.58	0.54	0.61	1.44	0.53	0.41
<u>Co:</u>						
$\bar{x}$	0.23	0.48	0.38	0.70	2.12	4.05
SD	0.23	0.50	0.31	0.58	1.24	2.59
<u>Af:</u>						
$\bar{x}$	0.73	0.56	0.67	0.56	0.55	0.38
SD	0.34	0.31	0.31	0.40	0.13	0.11
<u>MO:</u>						
$\bar{x}$	0.76	1.02	1.04	1.27	0.75	1.04
SD	0.32	0.41	0.43	0.61	0.37	0.32
<u>mo:</u>						
$\bar{x}$	0.02	0.02	0.12	0.16	0.18	0.16
SD	0.03	0.06	0.13	0.16	0.14	0.09

Table 8
Percentages of Affect by Type, Quality,
and Intensity for Subgroups

	<u>Low (N=19)</u>		<u>Middle (N=11)</u>		<u>High (N=10)</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
Positive:						
$\bar{x}$	54.47	66.26	66.64	73.36	62.30	68.30
SD	22.01	20.04	10.51	16.70	14.12	17.14
Negative:						
$\bar{x}$	45.53	33.74	33.36	26.64	37.70	31.70
SD	22.01	20.04	10.51	16.70	14.12	17.14
Appropriate:						
$\bar{x}$	84.11	82.95	87.36	86.27	96.40	91.40
SD	16.23	15.22	14.29	10.20	5.87	9.66
Inappropriate:						
$\bar{x}$	15.89	17.05	12.64	13.73	3.60	8.60
SD	16.23	15.22	14.29	10.20	5.87	9.66
Active:						
$\bar{x}$	82.58	84.89	87.00	85.91	90.50	96.00
SD	29.92	22.46	13.26	13.99	20.30	7.76
Passive:						
$\bar{x}$	12.16	9.84	13.00	14.09	9.50	4.00
SD	22.46	9.35	13.26	13.99	20.30	7.76

Table 9a

Intercorrelations of the Hierarchical Dimensions,
Pre and Post, for the Low Subgroup

		<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>
<u>M:</u>	Pre	-	.24	.19	.22
	Post	-	.20	.08	-.14
<u>En:</u>	Pre		-	.25	.20
	Post		-	.46*	.34
<u>So:</u>	Pre			-	.33
	Post			-	.72*
<u>Co:</u>	Pre				-
	Post				-

Table 9b

Intercorrelations of the Hierarchical Dimensions,
Pre and Post, for the Middle Subgroup

		<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>
<u>M:</u>	Pre	-	.68**	.32	.66**
	Post	-	.51*	.45	.43
<u>En:</u>	Pre		-	.42	.62*
	Post		-	.47	.18
<u>So:</u>	Pre			-	.74**
	Post			-	.14
<u>Co:</u>	Pre				-
	Post				-

* p < .05

**p < .01

Table 9c

Intercorrelations of the Hierarchical Dimensions,
Pre and Post, for the High Subgroup

		<u>M</u>	<u>En</u>	<u>So</u>	<u>Co</u>
<u>M:</u>	Pre	-	.67*	.07	.22
	Post	-	.21	.39	.48
<u>En:</u>	Pre		-	.03	.39
	Post		-	.48	.12
<u>So:</u>	Pre			-	.43
	Post			-	.21
<u>Co:</u>	Pre				-
	Post				-

* $p < .05$

Table 10a

Log Data: Ceiling Age Levels and Subgroup Status

	<u>Low (N = 19)</u>		<u>Middle (N = 11)</u>		<u>High (N = 10)</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
$\bar{x}$	10.21	12.16	17.18	17.91	19.40	23.10
SD	3.42	2.01	3.57	4.28	3.47	3.35

Table 10b

Videotape Data:
Ceiling Age Levels and Subgroup Status

	<u>Low (N = 19)</u>		<u>Middle (N = 11)</u>		<u>High (N = 10)</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
$\bar{x}$	10.21	11.79	13.27	15.54	21.60	23.10
SD	3.14	2.04	4.94	6.46	5.02	4.33

Table 11

Level Analysis of Verbal Expressive Communication
by Subgroups

	<u>Low (N = 19)</u>		<u>Middle (N = 11)</u>		<u>High (N = 10)</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
$\bar{x}$	4.32	8.84	10.99	13.55	22.20	27.20
SD	3.61	4.22	3.62	4.30	8.85	8.59

Table 12

Correlations between MA and the Seven
Psychoeducational Dimensions for the Three Subgroups

		<u>Low</u> (N = 19)	<u>Middle</u> (N = 11)	<u>High</u> (N = 10)
<u>M:</u>				
	Pre	.53**	-	-
	Post	.49**	.64*	-
<u>En:</u>				
	Pre	.54**	-	-
	Post	.54**	-	-
<u>So:</u>				
	Pre	-	-	.67*
	Post	-	-	.68**
<u>Co:</u>				
	Pre	-	-	-
	Post	-	-	.62*
<u>Af:</u>				
	Pre	-	-	-
	Post	-.50**	-	-
<u>MO:</u>				
	Pre	-	-	-
	Post	-	-	-
<u>mo:</u>				
	Pre	-	.59*	-
	Post	-	.75**	-

* p < .05

** p < .01

Table 13

Pre and Post Means and Standard Deviations of z Scores
In the Seven Psychoeducational Dimensions by Subgroups

	<u>Low (N = 19)</u>				<u>Middle (N = 11)</u>				<u>High (N = 10)</u>			
	<u>Pre</u>	<u>Post</u>	<u>T</u>	<u>T</u>	<u>Pre</u>	<u>Post</u>	<u>T</u>	<u>T</u>	<u>Pre</u>	<u>Post</u>	<u>T</u>	<u>T</u>
<u>M:</u>	<u>$\bar{x}$</u>	-0.90	-0.41	9.5	0.27	0.92	8.0	18.0	0.76	0.37	18.0	NS
	<u>SD</u>	0.41	0.62	$p < .01$	0.91	1.02	$p < .05$		1.04	0.70		
<u>En:</u>	<u>$\bar{x}$</u>	-0.28	-0.07	53.0	0.05	0.33	23.0	18.0	0.06	0.39	18.0	NS
	<u>SD</u>	0.84	0.81	NS	0.90	1.12	NS		1.10	1.50		
<u>So:</u>	<u>$\bar{x}$</u>	-0.70	-0.48	51.5	-0.10	0.85	2.0	0	0.18	1.25	0	$p < .01$
	<u>SD</u>	0.59	0.55	NS	0.62	1.46	$p < .01$		0.54	0.42		
<u>Co:</u>	<u>$\bar{x}$</u>	-0.53	-0.31	51.0	-0.43	-0.24	11.0	0	0.63	1.82	0	$p < .01$
	<u>SD</u>	0.14	0.39	NS	0.19	0.36	$p < .05$		0.76	1.59		
<u>Af:</u>	<u>$\bar{x}$</u>	0.44	-0.09	39.0	0.25	-0.10	20.0	13.0	-0.12	-0.46	13.0	NS
	<u>SD</u>	1.11	1.00	$p < .05$	1.01	1.28	NS		0.41	0.62		
<u>MO:</u>	<u>$\bar{x}$</u>	-0.46	0.13	6.5	0.19	0.83	16.0	10.0	-0.40	0.18	10.0	$p < .05$
	<u>SD</u>	0.73	0.92	$p < .01$	0.98	1.46	NS		0.83	0.72		
<u>mo:</u>	<u>$\bar{x}$</u>	-0.62	-0.59		0.29	0.61		19.5	0.74	0.56	19.5	NS
	<u>SD</u>	0.28	0.46	NS	1.08	1.33	17.0		1.18	0.75		

Table 14

Differences among Subgroups
on Pre and Post z Scores

		<u>Low vs Middle</u>		<u>Low vs High</u>		<u>Middle vs High</u>	
		<u>U</u>	<u>p</u> <	<u>U</u>	<u>p</u> <	<u>U</u>	<u>p</u> <
<u>M:</u>							
Pre	23.5	.002	Middle>	5.0	.002	High>	42.0 NS
Post	27.0	.002	Middle>	39.5	.02	High>	32.5 NS
<u>En:</u>							
Pre	80.0	NS		76.0	NS		53.5 NS
Post	83.0	NS		82.0	NS		50.5 NS
<u>So:</u>							
Pre	101.0	NS		28.0	.002	High>	42.0 NS
Post	24.0	.002	Middle>	0	.002	High>	25.5 .05 High>
<u>Co:</u>							
Pre	60.5	.10	Middle>	4.0	.002	High>	5.0 .002 High>
Post	82.5	NS		4.0	.002	High>	2.0 .002 High>
<u>Ar:</u>							
Pre	93.5	NS		71.5	NS		41.5 NS
Post	99.5	NS		73.5	NS		49.0 NS
<u>MO:</u>							
Pre	63.5	.10	Middle>	80.5	NS		31.5 NS
Post	81.5	NS		90.0	NS		44.0 NS
<u>mo:</u>							
Pre	33.5	.002	Middle>	19.0	.002	High>	41.0 NS
Post	22.5	.002	Middle>	13.5	.002	High>	48.5 NS

Table 15a

Number of Children in Each Subgroup Exhibiting
Positive, Negative, or No Change in z Scores
in the Seven Psychoeducational Dimensions

		<u>Subgroups</u>			<u>Total</u>
		<u>Low</u>	<u>Middle</u>	<u>High</u>	
<u>M:</u>	+	8	8	2	18
	0	11	2	3	16
	-	0	1	5	6
<u>En:</u>	+	5	3	1	9
	0	11	8	8	27
	-	3	0	1	4
<u>So:</u>	+	6	5	9	20
	0	10	6	1	17
	-	3	0	0	3
<u>Co:</u>	+	4	1	8	13
	0	15	10	2	27
	-	0	0	0	0
<u>Af:</u>	+	2	2	2	6
	0	7	5	4	16
	-	10	4	4	18
<u>MO:</u>	+	10	5	7	22
	0	9	4	1	14
	-	0	2	2	4
<u>mo:</u>	+	2	4	3	9
	0	15	4	2	21
	-	2	3	5	10

Table 15b

Differences Between Subgroups in Direction of Change
in z Scores in the Seven Psychoeducational Dimensions

	<u>L vs M</u>	<u>L vs H</u>	<u>M vs H</u>
M	5.49	11.48**	6.43*
En	1.98	1.49	1.96
So	2.11	9.04*	2.87
Co	0.11	7.11**	8.05**
Af	0.83	0.66	0.06
MO	3.72	6.79*	2.09
mo	5.49	9.55**	1.26

* $p < .05$

** $p < .01$

Table 16

Pre and Post Means and Standard Deviations
Of z Scores for Modifiers by Subgroups

	<u>Low (N = 19)</u>			<u>Middle (N = 11)</u>			<u>High (N = 10)</u>		
	<u>Pre</u>	<u>Post</u>	<u>T</u>	<u>Pre</u>	<u>Post</u>	<u>T</u>	<u>Pre</u>	<u>Post</u>	<u>T</u>
<u>IND:</u>									
$\bar{x}$	-0.83	-0.31		-0.02	0.69		0.12	1.31	
SD	0.56	0.89		0.56	0.81		0.67	0.97	
			19.0			1.0			2.0
			p<.01			p<.01			p<.01
<u>Passive:</u>									
$\bar{x}$	0.59	0.35		-0.34	-0.39		-0.48	-0.72	
SD	1.52	0.87		0.59	0.45		0.56	0.23	
			80.5			22.5			2.0
			NS			NS			p<.02
<u>Active:</u>									
$\bar{x}$	-0.85	-0.36		0.11	0.73		0.25	1.11	
SD	0.76	0.73		0.74	0.94		0.71	0.79	
			36.0			13.0			3.0
			p<.02			NS			p<.01

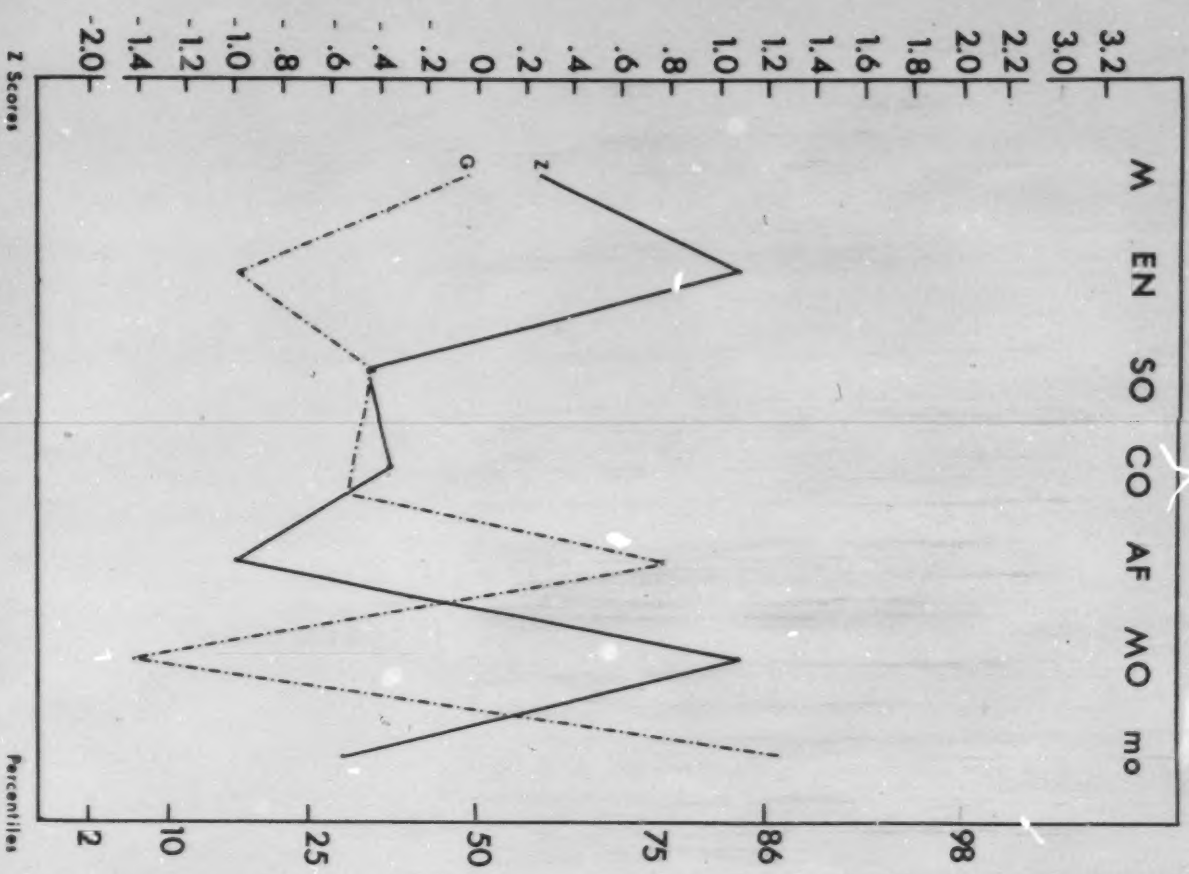
Table 17

Differences in Pre and Post Levels
of Functioning (z Scores) for Modifiers
Low, Middle, and High Groups

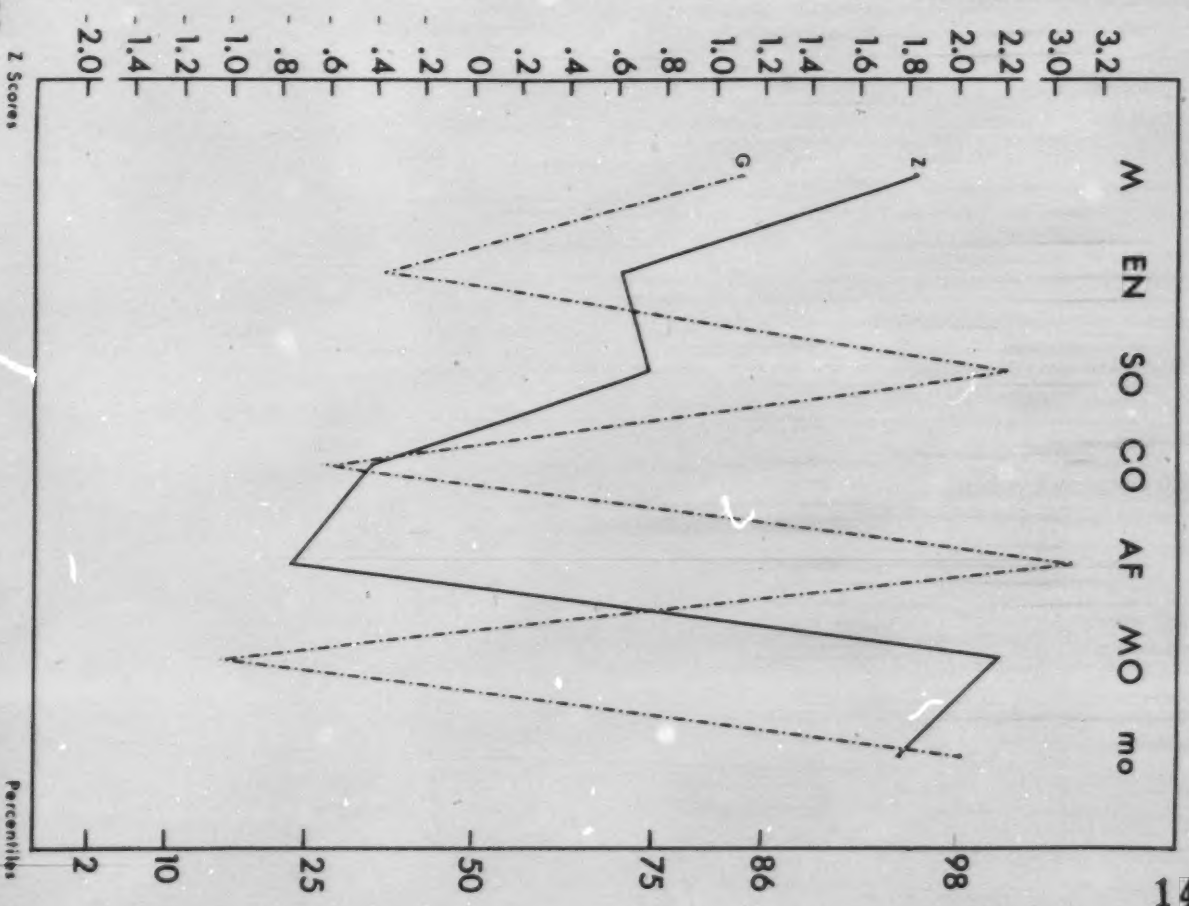
<u>Pre:</u>	<u>IND</u>	<u>Passive</u>	<u>Active</u>
L vs M	U = 29.0 p<.001	U = 49.5 p<.01	U = 38.5 p<.01
L vs H	U = 31.5 p<.01	U = 37.0 p<.01	U = 27.0 p<.001
M vs H	U = 44.5 NS	U = 47.0 NS	U = 47.0 NS
<u>Post:</u>			
L vs M	U = 43.0 p<.01	U = 43.0 p<.01	U = 39.0 p<.01
L vs H	U = 24.0 p<.001	U = 12 p<.001	U = 14.5 p<.001
M vs H	U = 34.5 NS	U = 18.0 p<.01	U = 43.0 NS

PROFILES OF CHILDREN Z AND G BASED ON Z SCORES WITH PERCENTILE EQUIVALENTS

a. Pre Period



b. Post Period



Case Study of Child JInitial Data and Impressions

J, a child medically diagnosed as "hypotonic with delayed developmental milestones," has been followed since one month of age by Dr. G. The youngest of the 11 children in her close-knit family, J was born after a pregnancy during which her mother reported periods of weakness. There was also a sudden weight loss towards the end of the pregnancy. Fetal activity was felt, and was of "normal intensity." Following J's birth it was noticed that she had poor muscle tone; she was placed in an incubator and had to be fed by gavage (tube), and was kept in the hospital for an extra week. She was felt to be a "floppy infant". At 19 months of age she was referred to the Institute's Infant Program.

When admitted to the program at 23 months, J gave the impression of a cute (although obese), curly-haired child who was smiling and pleasant. J was markedly passive, "flat" in affect, and was not fearful of strangers. She showed no evidence of separation difficulties, although this type of anxiety, tension, or upset is to be expected in a child of her age. Language production was delayed. The staff speech pathologist's assessment reported an overall language age of approximately 1 year. Psychological evaluation (using the Bayley Scales) revealed a scattering of abilities ranging from 13 to 17 months, with spontaneous performance leveling off at 15 months. Motoric development was also delayed. J had just started to walk and exhibited a "beginning toddler" wide-based gait. Her balance was good; there were no problems in the upper extremities.

Data Prior to Admission

The first impressions of J were those obtained during the initial screening session. At that time J was a heavy, floppy 22-month old. It was evident that, although J was functioning well below age level, she did have the concept of playing with toys. The first activity involved removing a single one-inch peg from a peg board and placing it in a basket. J repeated this twice. Visual interactions and babbling with the examiner were found throughout the session. Following this were a series of tasks requiring J to remove objects. After a brief hesitation, she succeeded in each of these: discs from a spindle, beads from an abacus, and separating nesting cups. Each task was completed after assistance by the examiner; J was then able to complete the tasks independently. J also successfully replaced a peg in a pull toy. As the session progressed, it became evident that J was equally interested in exploring the shelves, the objects, and the people in the room. She maintained almost continuous verbal contact through undifferentiated babbling and use of single words, "one," "more".

The overall impression was of an attentive child who could persist in achieving whatever goal has been designated (from a selection of simple tasks) but who had ideas and goals of her own, which she assertively pursued.

Log Data

J was admitted approximately 1 month after the initial educational screening. She was now 23 months old and weighed 37 lbs. Her entrance into the room demonstrated that this was a child who could make her own decisions and choices of activities available. After being placed on the floor, J crawled directly to the small rocking chair. J's first 10 days in Infant Program included a tremendous amount of active exploration of the room, of the adults, of the children, and of materials. She picked up most materials presented to her, a ball, some cylinders, and some cards, but rarely did more than manipulate them in her hands. There was an indication, however, of some higher level of awareness. She appropriately replaced a square and a circle in a form board. Her gross motor activity also gave evidence of competency. She could throw a ball with two hands with good coordination and could drink from a cup held in one hand while she held a cookie in the other. She could already ambulate independently, pull herself up to a chair, and get off the chair with minimal assistance. As was evident in the initial screening, J initiated many of these actions and activities, asserting her own will.

A quantitative analysis of the anecdotal records from this time period indicates that a quarter of all behavior involved interactions with materials. Fifty percent of these were simple manipulations and explorations. The remainder represented tasks which she completed. Those tasks successfully completed were, on the average, at a 21-month level.

Socially, J was aware of and interested in children and adults. She did not, however, become involved in extended interactions. When language accompanied interactions, it consisted only of single words, "bye" and "ba" for ball.

The largest proportion of J's behaviors involved gross motor activity (32%), with a larger proportion of fine motor activities (4%) than is evident in most children in the Infant Program.

By the end of J's second week, it was evident that she had some degree of competency with materials, social situations, large muscle coordination, and fine motor skills. J's language was the area of most severe delay.

Goals while on Program

Based upon initial performance, the infant school staff defined goals for J which would incorporate more differentiated experiences. Thus, gross movements would include dancing in the teacher's arms and rocking in the adult rocking chair. In addition to expanding kinesthetic sensations, textures would be introduced to stimulate tactile awareness. Labeling of objects and facial features was also to be incorporated into J's daily program.

Verbal labeling continued to be a goal throughout J's time in Infant Program. This was incorporated into her exposure to a wider range of materials. J was encouraged to explore cabinet shelves which were organized specifically for her to include peg boards and rhythm instruments. In addition, specific toys were selected to extend her already existing competencies with materials. For example, J had first inserted the cylinder in the form box through trial

and error. Later she was able to pre-judge the proper place for inserting the cylinder in the form box. After this the same form box was introduced both with a cylinder and a square. Similar types of extensions were developed for water play, with changes from splashing to scooping and pouring. In the area of social awareness, the teachers' goals were to encourage J to extend her interactions with other children. It was decided to set up a parallel play situation for one period per day with another child working close to her developmental level.

Data Prior to Discharge

Following a week at home (during Easter vacation and during which she had a bad cold), J returned for her last 2 weeks on Infant Program. Water play, turning the faucets on and off, and washing objects with "handi-wipes" were among the activities that J most frequently initiated and enjoyed.

When presented with more structured materials, J's interest appeared to be reduced, even in tasks she had formerly completed with ease (i.e., inserting large pegs in a peg board). Emphasis was placed upon form discrimination, distinguishing between the cylinder and cube in the form box. J could quickly insert the cylinder each time. However, even after repeated demonstrations, she did not seem to grasp the idea of rotating the cube so that it could be inserted in the square hole.

J's overall responsiveness to materials and the environment seemed erratic during these last 2 weeks. A great deal of time was spent in aimless wandering. Seeing some pop-up people on the shelf, she might begin by pushing them and watching the resultant action. After removing some metal cups and saucers from a container, J shifted from an organized setting of the table to dropping the objects and watching them rattle. There was increased interest in her surroundings and her walks down the hallway were punctuated by looking into every doorway.

Interactions with people followed a similar pattern. If a child came up to J and touched her, she frequently would have little or no response. However, if she saw a stranger enter the room, she suddenly would become very animated, walked over to him, and say "hi".

Other than a consistent "hi" and the use of "ma ma" to get the attention of any female adult, J's language was almost exclusively imitative. She made her needs known through gestures and facial expressions. J's ability to ambulate independently made it possible for her to have access to whatever material she wanted without additional assistance.

The overall impression of J just prior to discharge appeared to be one of a child who no longer derived sufficient pleasure from the materials, the room, and the people with whom she had spent 3 months. Her most pleasure and greatest initiative were evident in finding and exploring new people, new environments (the hallways and playground), and new experiences.

The proportion of codeable behaviors in each of the seven dimensions during these last 2 weeks were almost identical to the first 2 weeks. There was an increase of 5% in communication skills, represented more by the refined use of symbolic gestures than by an increase in verbal ability. A slight rise in the

proportion of fine motor skills used in conjunction with materials was also evident. The rise in both of these areas accounts for a decrease of 6% in the proportion of behaviors coded as gross motor. The largest proportion of behaviors was in the dimension of Interaction with Materials (28%). J completed 42% of all tasks appropriately, at the level of a child of about 18 months. In another 22% of her interactions with materials, she appeared to understand what was asked of her but either could not or would not complete the activity. On the average, each episode of behavior contained approximately one interaction with materials.

Videotaped Re-Evaluation

Two days prior to J's discharge a videotape was completed using many of the same materials employed in the screening session 5 months prior. In the first session J had only been able to remove beads and discs from spindles; she was now able to replace several of each. At the highest level, J could also quickly insert cylinders into a form box. J's clear preferences for certain materials, such as the xylophone, were a striking feature of this session. She initiated both visually and active exploration of the surroundings. Interaction with the examiner was limited to simple responses and occasional babbling. As in the logs written in the classroom, one is struck more by the assertiveness and independence of J's behavior than by the quality of the activities, which averaged only at a 15-month level.

Overall Impressions of Change

Observed and recorded changes should be viewed within the context of J's being the youngest of a close 11-child family and our original impressions of J's status upon admission in that:

- (1) She exhibited little overt problems with separation. In fact, she was "flat" in emotional tone;
- (2) She had few extended interactions with people, children, or adults;
- (3) She had just started to walk upon admission.

We can conjecture that for this youngster separation from her large family was more traumatic than was demonstrated overtly. (After a holiday and illness, it was difficult for J to leave home and re-enter the Infant School.) Preoccupation with exploration using her comparatively new ability to walk impinged upon her satisfaction from extended periods of sedentary play with structured materials; that the foundations for emerging skills were laid during these 3 months but that gains might be seen after discharge and after re-entry into the comfort of a home situation. The latter premise appeared to be at least partially substantiated by a dramatic change observed and reported in J's communication skills during her admission and year's progress in our Out-patient Program at IRM. A referral was subsequently made to a nursery school for "normal" children. J is now attending that neighborhood school. Reports from her teachers indicate that she is increasing her language skills and is more active in her interactions with peers socially.

Case Study of Child O

Initial Impressions

Child O is a delicate looking, shy, and quiet Oriental child who acquired cerebral palsy as a result of meningitis at the age of 4 months. At that time the family was living in Hong Kong. All but the father have since emigrated to New York City. The mother now works as a legal secretary.

O was first seen at IRM at the age of 28 months for a complete medical evaluation. At that time it was noted that she had a left spastic hemiparesis with shortness of both upper and lower extremities on the left side. In addition, her head size was more than two standard deviations below normal. The general impression of the pediatrician was that she was delayed in development.

The psychologist's initial evaluation, based on clinical impressions rather than on test data (since O would cooperate for only short periods of time) was of a child functioning about 18 months. Intense separation problems between O and her mother were also noted.

The report of the physical therapist indicated that, while O was delayed motorically (she did not crawl or walk), she had the ability to move about the room on her buttocks and could maintain a sitting position. Her left arm was kept in flexion, and O became extremely irritated when asked to use her left hand.

Evaluation by the occupational therapist revealed that O could use her right hand normally to the extent of having "a neat pincer grasp." Activity with the left hand was initiated by O for play and finger feeding; however, objects were usually transferred to the right. Overall impression was of a child with hand use comparable to that of a 12-month old child.

In terms of language usage O was evaluated at about the 18-22 month old level, using mostly single words and several two-word phrases in English (e.g., "hold me," "no sleep," "mommy come"). The child's native language is Chinese; her mother estimated that she knew about 50 Chinese words. There had been some concern about a possible hearing loss. In the informal testing session O appeared to hear normally, but audiometric evaluation was recommended.

The overall impression of O, based on a composite of all therapies, was of a child functioning about 12 to 18 months of age. Separation of the mother and child was considered to be a problem by all who had contact with them.

Log Data

From the first day that O entered the Infant Program, she exhibited interest in materials. She removed discs from a spindle and large pegs from a peg board. When given a set of hollow plastic blocks to stack, she first "looked them over" and then began to explore them with her right hand. O readily became interested in unstructured materials as well. Water play began with

simple splashing. Eventually O accepted extending this to washing a doll and using a scoop and a long-handled ladle.

O's awareness of the environment was focused primarily on individuals. From the very beginning she showed a clear preference for and trust in male figures. This was evidenced by her joyous and excited greeting of the pediatrician who had entered the room in the midst of what had been a tearful session. O directed her tears and anger at her mother; this was thought to be in retaliation for having been left with strangers. On her mother's second visitation day, O gave her mother a cool expressionless greeting. The mother reacted with verbal annoyance, and O commenced agonizing crying, which did not cease for the remainder of the morning. On the whole, however, O was a quiet child who cooperated with her therapists and smiled frequently at the teachers and children in the room.

O's ability to interact with materials and with individuals was slightly hampered by her motor impairment. She could move about the room on her buttocks and could walk when supported. When unable to change positions (such as getting down from her chair) O let her needs be known by gestures, jargon, and short phrases.

There were indications of independence. At times O initiated social interactions. When she no longer wanted to be involved with a material, she would either push it aside or say "bye," indicating that she was ready to stop.

The developmental profile from the quantitative analysis of the log data reflected equal time spent in functioning in materials (21%), social interactions (23%), expressive communication (20%), and gross motor skills (19%). The remainder of the codeable behaviors were in affect (15%), environmental awareness (2%), and fine motor ability (1%).

O's work with materials often indicated awareness of the goal without the ability to successfully complete the designated task. Those activities which she completed competently were at about the level of a 14-month old child. Social interactions, which were usually accompanied by verbal and non-verbal communications, were usually of short duration. This was true except for extended interaction with her mother. In these instances strongly negative but appropriate affect predominated. The independence of this child is reflected by the fact that each episode contained, on the average, at least one behavior which could be coded as self-initiated or assertive.

Videotape Data

Approximately 3 weeks after O's admission to Infant Program, O's status was assessed in a psycho-educational evaluation session with the Project Director. This session, involving about 12 structured and unstructured materials, was videotaped and subsequently analyzed by an independent research team. The specific focus at that time was on interaction with materials. Two-thirds of these interactions indicated that O knew the goal of the activity, even if motor problems interfered with completion. During the course of this session, O initiated both brief and extended interactions with the examiner. She also responded to the examiner's attempt to involve O in the construction

of a block tower. Verbal communication in terms of babbling and an appropriate use of "more" was evident during this session.

Overall impressions based on this tape were of an assertive child who interacts with materials at the level of a child of approximately 14 months. At the lowest level were simple activities such as hitting a xylophone and pulling a pull-toy. On a slightly more complex level O could scoop and pour sand and could insert one-inch cubes in a plastic bottle and dump them.

Goals and Activities

Based upon behaviors exhibited within the classroom during the first few weeks and the videotaped session, the initial goals were directed toward working through separation problems prior to focus on materials. Before working towards extending her level of functioning, it was necessary to initiate activities which would require bi-lateral use of her hands. By the second month in the Infant Program, O began to use threading toys, peg boards, and nesting sets. These activities were later extended to include more refined discriminations and differentiations (e.g., between squares and circles). Eventually the work with materials became secondary to extending O's overall exploration of her environment and developing greater interest in independent ambulation.

Data and Impressions Prior to Discharge

A review of logs written during the 2 weeks prior to O's discharge show that she was working competently in almost every activity. Much of her time was spent in exploration of the environment and in experimenting with her newly acquired ability to ambulate independently. At times O attempted to ambulate beyond her skill and ability; this necessitated a great deal of supervision by the adults in the room. Most activities and social interactions were accompanied by verbalization in the form of single words and two-word phrases. She connected words not only with actions -- "up," "down," "eat," etc., but also with objects, "chair" and "baby". At times O indicated an awareness of the "labeling function" of language by touching an object and then looking to an adult for the appropriate verbal label. This label was then carefully imitated.

The presence of Mrs. O was still cause for some anxiety, reflected by crying. It was only on the last day that O's mother participated in the program that O could accept her mother's departure without tears and anger. Aside from reactions to her mother, affect was predominantly positive and was always appropriate to the situation.

These logs portray a child who is essentially social (55% of all behaviors were coded as social responsiveness). These social interactions were coupled with a great deal of expressive communication (27%). Another 21% of the behaviors were gross motor activities. At this time interaction with materials represented 11%, affect 10%, and fine motor ability 3%.

Almost 90% of all work with materials indicated that O was aware of what to do with specific materials or tasks. O was now working at the level of a child of approximately 15 months. This may be a reflection of the comparatively low level of the group present in the Infant Room at that time. At the highest level O exhibited a keen interest in using finger paints, employing both hands alternatively with individual streaks with her fingers. She also carefully looked through a story book pointing at each picture. The remainder of her interaction with materials was active explorations of the materials. When considering each episode independently, there was an average of at least one social interaction, verbal, and/or gestural communication per episode. These behaviors were combined with self-assertion or self-initiation.

A videotape completed during this same period showed a child functioning at about 19 months. The discrepancy between log data and videotape data reinforces the idea that her functioning within the room was affected by the other children present at that time. The materials used during this session were almost identical to those used 3 months before. At this time O could build a two-block tower, complete a six-cylinder peg board with one-inch pegs, nest two cubes, and remove all beads and replace some beads on an abacus. Almost every task was accompanied by a verbalization "out," "more," "in," "mouth," "move," and "walk." O functioned without the need for directions of the examiner.

Impressions and Additional Data Prior to Discharge

The medical picture of O showed little change by the time of discharge. There was a recommendation for surgery and for glasses to correct a visual defect. The re-evaluation of O by the speech pathologist indicated that O had made significant gains in this area. There was a language delay, with a limited vocabulary for a child her age, but with appropriate grammatical structure. The basic recommendation on this basis was for a program of language stimulation, which would be best provided within a nursery school setting rather than in sessions of individual therapy.

A psychological evaluation completed at discharge was based upon portions of the Bayley Scales of Development, Gesell Development Scales, and the Preschool Attainment Record. The conclusion was that this child would continue to have difficulties because of low visual-motor and organization abilities.

A dramatic improvement was found in motor skills -- balance and gait. By the time she was discharged, O could walk four steps without support.

The impressions of her teachers were that O had made significant changes which "culminated in a spirit of growth in all areas of development." This included more organized work with materials, affect which was of normal for a child her age, and an ability to accept her mother's participation day. "Having once achieved this, she gained more strength and became eager to demonstrate her new abilities for her mother." On the basis of these gains it was recommended that O return to IRM and attend the Nursery School two mornings per week with additional periods of physical therapy and speech and hearing stimulation.

At the present time O attends a pre-school Day Care center for normal children where she is doing well.

Case Study of Child T

Initial Data and Impressions

Impressions during screening were of a slightly built, dark-haired child with a warm and charming manner. Both T's movement and speech suggested the pattern of a delicate child. However, his eyes suggested vitality, alertness, and awareness. At the time he was living with his father and his paternal grandmother. The grandmother, solely Spanish-speaking, was his prime caretaker, while T's father (who spoke English fluently) attended college. T's family was supported by public assistance.

Upon admission into the Infant Program, T, a child medically diagnosed as "congenital cerebral palsy," was 24 months of age. His condition was classified as a mild spastic diplegia with little involvement in the upper extremities and spasticity in the lower extremities. With his good balance and head control he was able to move and "cruise" from one part of the room to another by holding onto furniture or onto someone's hands. The presumptive etiology of his neurological condition was the prematurity of his birth (7 months gestation) and the possible added factor of maternal drug addiction. (T was the first born of twins; the second child was stillborn. Birthweight was low, 2 lbs., and he spent his first month in an incubator.) Other medical parameters (i.e., vision and audition) were evaluated to be within normal limits. Mental age (based on psychological testing) was assessed at approximately an 18-month level. Speech Pathology reported an expressive vocabulary of some five to ten words in English and Spanish (usage was equivalent).

Data from Anecdotal Records

A qualitative and quantitative analysis of anecdotal records (logs) written by the teachers during this pre period indicated that T was competently able to cope with a great number and variety of age-specific activities with materials. He could fill and empty containers, use a telephone appropriately (babbling into it), turn water faucets on and off, insert pegs of varying sizes into holes, cover nesting cups, and was able to thread chain links onto an adult's fingers. T worked diligently but had difficulty with materials which required more refined eye-hand coordination and fine motor ability (i.e., puzzles and form boards requiring the rotation of pieces or tasks involving threading objects onto spindles). He explored and manipulated materials experimentally to discover their properties. For example, T manipulated the discs on a color cone by spinning them. He then noticed that they slid up and down and could be removed. He then proceeded to remove and rethread the discs onto the spindle with some teacher assistance.

In some instances he was able to extend the use of materials. Using his teeth to supplement his grasp with both hands, he was able to remove the cap from a plastic 2" tube and then drop the 1" cubes into it -- all without putting any of the materials down.

T's exploration of materials may be viewed in the broader context of curiosity about and self-initiated exploration of his new environment in the Infant Room. He explored cabinets and cubbies and listened to the sound of running water.

There was also some evidence of differentiation, association, and anticipation. He appropriately associated the teacher's moving to the coat closet with her leaving for the day, as well as eating of cookies with being seated at the table. After being promised a cookie, "when we get back to our room, " T remembered and correctly requested the "cookie" as soon as he returned to the infant room.

T was socially trusting and responsive, greeting familiar people with smiles, waving, and "bye-bye". The majority of his language consisted of single words and some two-word phrases. He referred to his father as "poppy" and used other single words such as "cookie" and "baby," "bye-bye" and "O.K., bye". In addition, T had a vocabulary of single Spanish words. Affect (both negative and positive) was consistently appropriate to the situation.

T crawled and cruised as varied means of locomotion. When held from behind, T was able to walk on his toes. His feet "scissored". He was able to pull to standing position by holding onto furniture. He only stood if supported. He was able to maneuver about in a low cart (spina bifida cart) using both hands to rotate the wheels and direct the cart's movement. T could use his hands effectively, though there was evidence of slight incoordination in more refined activities (i.e., threading objects or inserting pegs into holes).

Data from Quantitative Analysis of Logs

Examination of data derived from the coding and analysis of logs of the first 2 weeks of T's admission disclosed that a quarter of all behavior was coded in the dimension of Interaction with Materials. (When the level analysis was used to refine further behavior within this dimension, a mean age level of 17 months was obtained for level of competency in work with materials.) The remainder of behaviors recorded was almost evenly divided among the other dimensions of the coding system: Environmental Awareness, 10%; Social Responsiveness, 14%; Expressive Language, 13%; Affect, 14%; Gross Motor Ability, 15%; and Fine Motor Ability, 10%.

The most striking feature of this performance profile is the high proportion of fine motor ability recorded -- higher than that of the majority of the children in the Infant Program. This is of particular interest if we simultaneously recognize that T was one of the youngest children enrolled in this program. All situations reported by the teachers reflect a high level of alertness and activity in this youngster; the reporting of passive behavior was minimal.

Data from Videotaped Diagnostic Work Session

Examination of a videotaped diagnostic work session with educational materials yielded confirmatory data. The initial videotape on T was recorded only a few days prior to his admission to the Infant Program. In this session he appeared to be at ease and comfortable with the situation, the examiner, and the new materials being presented.

On 10 of the 12 structured tasks T independently assessed the goal implicit in the materials and completed the task without assistance. Demonstration was required in a containment problem involving the insertion of 1" cubes into a plastic milk bottle with a 2" neck; he then completed the task independently.

Even while working with unstructured materials (i.e., sand and water), his early primitive experimentation quickly moved to more complex and competent use of scoops, bowls, and assorted objects -- all in an organized and explorative manner. Level of functioning was 17 months.

Throughout the entire session there was a continued visual and verbal exchange with the examiner. His speech, though limited to "in," "one," "two," and "hello" in this session was appropriate and clear. In addition to the use of these specific words, there was evidence of babbling with inflection.

T's attention did occasionally wander from the materials to the room and to outside sounds, suggesting that T was aware of and responsive to stimuli from the larger environment but was able to refocus on the task at hand.

Educational Goals Established by Teacher

The most highly refined education goals projected by the teachers were in relationship to materials. Focus was concentrated on both broadening T's experiences with materials, exposing him to unstructured materials such as water play and finger paints, and refining already established abilities. There was an increasing emphasis on form, shape, and size discrimination, all within the generalized framework of conceptualization of similarities and differences. These activities were planned to enable T to explore new materials and to increase and build new conceptual relationships. In order to augment further this exposure to new and higher level activities, T was scheduled for one hour per day in the pre-school after his first few weeks in the Infant Program. Here there would not only be a broader range of materials and activities but also potential for interaction with older and higher functioning children.

Socially T would be exposed to older and more mature models; parallel play would be encouraged. Verbalization was also an area of focus. Encouragement of more mature behavior and greater independence was also reinforced in therapy by the motoric goals of independent ambulation (with the use of a rollator as an intermediate step).

Data and Impressions Prior to Discharge

An examination of anecdotal records written by the teacher during the post period indicated qualitative and quantitative changes in functioning. (This post period commenced four weeks before discharge and covered a two-week time span). T could now work with more complex educational materials with increased task demands. He properly manipulated a jack-in-the-box and threaded a threading block with a string. He engaged in many containment activities including inserting beads into the compartments of a box. T could scribble with a crayon and paint with a brush. He was able to pull a zipper up and down, feed a bottle to a doll, and locate the eyes of a doll (upon instruction). He could turn the water on and off and could manipulate the drain by himself. T still needed some assistance with certain tasks requiring very fine motor ability (i.e., filling a small squeeze bottle with water and undressing a doll).

T now could extend the use of more materials and indeed used them creatively at times. For example, he stacked several egg cups on top of each other and, when given a bottle, funnel, and cup, stacked them as well. Anxious to reach a jack-in-the-box out of his reach, he used the lock box as a stool to bring the desired object within his reach. When the teacher put her pocketbook down for a minute, T put his arm through its handle and waved "good-bye". He continued to explore materials.

During the post period T continued to explore and examine all aspects of his environment. He climbed into cubbies and closets and examined the furniture. He was aware of and sensitive to changes of procedure or unusual events such as the appearance of a film crew or water changing color as food coloring was added. He noticed that his coat was covered with sand and leaves after playing in the sand pit in the playground and brushed off his coat. He enjoyed moving from one area of the playground to another and investigating the external surroundings by looking out the peek-holes in the treehouse.

T had clearly internalized the infant school routine. When given his coat, he anticipated a trip to the playground. He asked for juice when he spotted the juice container and when moved near the sink, he asked for "water" (in Spanish). He knew where materials were kept and where to find his personal belongings. When told to "get the juice," T knew that he needed to go to the refrigerator in another room and could find his way there without being side-tracked. He also knew and followed procedures, threw his cup into the wastebasket after juice, and appropriately looked around for the basket when he was finished drinking his juice.

Most of T's social interactions were brief but qualitatively sound. He sought attention, sometimes quite assertively, and asked questions. He also requested materials from others and occasionally sought assistance when needed. He found comfort in human contact and enjoyed comforting others. He told another child, "don't cry," and shared materials with the other children. He took great pleasure in adult praise and was upset when reprimanded.

T was able to follow verbal requests and usually accepted transitions well, with the exception of terminating activities with his father, which he still resisted. Some times a request to give up a material would still "set off" a minor tantrum.

Most of T's extended and involved social interactions occurred with his father, or with one teacher (during teasing games such as hiding in closets or tickling games). He initiated group games (follow-the-leader) after snack but did not otherwise usually engage in extended play with other children.

Many new words and word combinations were used. Expressive language included words such as: "car," "soap," "painting," "table," "juice," "in," "water," (both in English and Spanish), and "mop," "don't cry," "bottle," "more," "up," "sponge," "eyes," "down," "out," "good boy," "paper," "pour," and "open". He called the nursing aide by her first and last name and approximated the phrase "good morning" with "a-morning" accompanied by the proper inflection. He also said "elephone" for "telephone," "nana" for "banana," and "eavy" for "heavy". In addition to these single words and two-word phrases, T said, "I don't want it" (in Spanish).

Most of T's affect was positive prior to discharge. He laughed in response to social interactions and at his own accomplishments with materials. Negative affect was appropriate. He cried when placed in his crib, when his father departed, or when he was told that his father was leaving. Tears also accompanied the terminations of some satisfying activities and/or adult intervention.

T still could not lower himself to the floor from a standing position without assistance but could get into his own chair with some minimal help. T had become quite bold in some of the activities he attempted, i.e., crawling into a closet after emptying the contents of its shelves.

Data from Quantitative Analysis of Logs

At this point in time (post period) 15% of T's behavior involved Interaction with Materials. (The major shift was in the areas of Social Responsiveness and Expressive Language, with almost 45% of T's behavior reported in these areas. This was evenly divided between the two. Another 21% recorded as Gross Motor Ability. The remaining behaviors were distributed among Environmental Awareness (10%), Affect (9%), and Fine Motor Ability (3%). The proportional decrease in reports of fine motor activities and interaction with materials in the infant school logs can be explained by the fact that the majority of T's refined work with materials occurred during his programmed hour in pre-school. In contrast, the portion of T's morning spent in the infant room were periods that involved a "snack time" where there were fewer opportunities to explore and become involved in activities with unstructured materials. These periods encompassed behaviors that were reflected in a high reporting of Expressive Language and Social Responsiveness.

A similar analysis of T's work with materials for this post period indicates that on the basis of a level analysis of functioning, T was now functioning at 19 months. Although the proportion of time directly spent with materials is smaller, the quality and type of work reported continued to reflect interactions at the upper end of the level hierarchy. T was not only aware of the goals of materials but was also beginning to show evidence of being able to work creatively with materials according to his own understanding, intent, and desires.

Another significant change was the marked increase in T's vocabulary, which now contained 22 words. His expressed language recorded included several phrases in both English and Spanish.

Data from Videotaped Diagnostic Work Session

Two days prior to discharge, a second videotaped session was recorded. Many of the materials used in the pre sessions (pegs, xylophone, telephone, and sand) were repeated. Again he used these materials appropriately, occasionally extending them beyond the immediate goals implicit in their design. For example, the telephone became a means to answer the examiner, and the Morgenstern bead loop became a doorway for one of the peg people to enter. In addition, T demonstrated evidence of the ability to make discriminations. He was able to differentiate between cylinders and cubes for insertion in the form box. His ability to differentiate and recognize size gradations was evident by the speed with which he correctly nested three of four graded nesting boxes and then competently separated them. Level analysis was 22 months.

Although language usage was not the predominant focus in this semi-structured informal session with educational materials, there was a clear indication of T's level of expressive language in his initial question to the examiner, "What's that?"

Impressions and Additional Data Prior to Discharge

T spent approximately 3 months in the in-patient Infant Program. Dramatic change and progress were reported by the speech pathologist. Expressive vocabulary had grown in size to 40 words. In addition, T now produced word combinations. The clinical psychologist reported greater organization in problem-solving, with above-age level abilities in perceptual-motor and conceptual areas. In a discharge summary T was described as a child with "at least average intelligence."

After an intensive physical therapy program, which included mat activities, range of motion, activities for the lower extremities, and ambulation training, significant changes were also reported. T was fitted with a pair of short leg braces with orthopedic shoes. T was now able to walk independently for short distances. He had developed good protective equilibrium reactions and was now able to ascend and descend four-inch stairs by holding on to one handrail. This information, together with knowledge of changes in status in educational areas, was considered in determining an appropriate educational referral in his neighborhood.

Analysis and Interpretation of Change

An overall pattern of change was recorded while T was in the Infant Program. This reflected growth in all areas with a different degree of change occurring in varying dimensions. The greatest rate of growth was recorded in verbal language and social responsiveness. Growth and change in quality and content of work with materials and environmental awareness was gradual but consistent. Independent ambulation developed with concomitant greater mobility; fine motor coordination also improved.

Change in the use of materials was consistent with the teacher's projected intent to extend existing skills and to introduce T to less structured materials. Thus, throughout his stay, materials were offered sequentially in order to refine his ability to discriminate size, shape, and color. After the introduction of water play there was a continuous encouragement of extension of his play by the addition of supplementary materials and more elaborate types of accessories. Earlier records included simple pouring activities, while the later logs recorded T's use of funnels and more sophisticated objects.

The most significant changes occurred in T's development in the area of expressive language skill. The significant increase in T's imitation of words and appropriate use of language in social situations appeared to be clearly related to implementation of projected goals as outlined by the teachers in weekly planning sessions. The early goals for language development included an intent to lessen the perseverative use of words and to terminate obsessive hand banging as a means of expressing "no". The goals shifted towards increased symbolization with use of appropriate verbal labels.

Upon discharge there was an immediate referral (for the balance of the school year) to the out-patient Infant Program at IRM for further educational stimulation and physical therapy. This served as a transition before T was referred to and placed in a Day Care program for normal children. After several additional months in this pre-school program (two afternoons a week), T was referred to the neighborhood setting. Subsequent follow-up through reciprocal visits by staff were scheduled at this time. The educational staff and Physical Therapy Department have continued to monitor progress in all areas.

Case Study of Child LL

Despite his high birth weight (9 lbs., 8 oz.), child LL weighed under 20 lbs. when admitted to the Infant Program at the age of 31 months. The second child of a close-knit middle-class black family, LL had had a heart murmur since birth. By the time LL was 3 weeks old his mother noticed that he was having difficulties at feeding time, and subsequent examination in a hospital determined that there was a congenital heart defect. At the age of 11 months this defect was surgically corrected. In addition, LL has had pneumonia twice and has been, therefore, continuously medicated. His many illnesses may explain his fragility and failure to thrive. LL's parents pinpointed their frustration with his slow development by commenting on his lack of response even to his name.

Initial Impressions

Diagnosis at IRM was that of cerebral palsy with hypotonia secondary to a third nerve palsy. There was a partial light reflex in the left eye but none in the right. (It was reported that during the first 6 months there had been no visual reactions.) A partial facial weakness on the right was also noted. The etiology of this condition is not definite; however, LL's mother reported having had an upper respiratory infection early in her pregnancy. During her first pregnancy she had developed diabetes, and it is possible that this condition had reoccurred during this pregnancy.

The initial evaluation by the physical therapist indicated that LL had good range of motion in both the upper and lower extremities but had reduced muscle power, particularly in the shoulders and neck. When held in a sitting position, his head would lag. He preferred to push himself along on his back rather than crawl, supporting himself on his arms. He could not come to a sitting position but could maintain this position once placed in it. He did not come to standing but could stand with very close supervision. Once standing he tended to lose his balance easily because of his "self-stimulating neck extension."

The speech therapist indicated in her report that she suspected a hearing loss. In free-field testing there were poor responses bilaterally (no response to a drum, whistle, a knock, or the door or to babbling). There was some response to sounds made close to his right ear. On this basis an audiometric examination was prescribed. In addition to the possibility of a hearing loss, there was also a left facial paresis. Although LL sucked well, he could neither drink from a cup or chew. Overall language development was estimated at well below 6 months. Comprehension was at the same level; LL did not evidence different reactions to "yes" or "no".

One repetitive pattern noted by all the therapists was perseverative movements and a strange series of sounds. These movements included wiggling his hands in front of his eyes, often with his index finger and thumb in opposition and grinding of his teeth. He also made a "duck-like" noise. In addition, there was persistent crying which was not usually accompanied by tears and which did not cease even when he was comforted by someone.

During the initial evaluation period, LL was classified by all therapists as a low functioning child. His highest area of functioning at that time was motoric -- his ability to maintain a standing position when guarded. The medical prognosis was one of only limited change with 3 months in the program.

Infant School

The pattern of functioning reported by the therapists was also evident in the teachers' anecdotal records. This pattern was most evident in social situations. On the first day LL was in the Infant Program, he cried almost continuously, even when his mother or grandmother held him. His grandmother explained: "LL does not accept comfort from her (his mother) unless he's ready." The only means to reduce this crying was to place him on his back in his crib with a bottle. This pattern was frequently repeated during the first 2 weeks. Many times LL showed no indication that he was aware of the other individuals around him; there was neither eye contact nor a change of facial expression. On occasion he did purposefully reject social contact (a teacher trying to engage him in a hand game and a child coming into contact with him while on the floor).

Descriptions of LL's responsiveness to materials and to the surrounding environment were similar. Several objects such as a ball, tambourine, and disc were handled; many more were totally rejected and pushed aside. When the material employed was designed for exploration, LL occasionally showed appropriate use, such as raising a colored plastic disc to his face and rubbing his hands along a texture board. There were two activities in which LL even appeared to follow a sequence of steps such as removing a disc from a spindle and catching and releasing a plush covered car dangling from above.

The complete picture of LL during these first 2 weeks was extremely varied and puzzling. At times he seemed to be aware of his surroundings as indicated by his moving over to a closed door and then opening and closing it. The majority of the time, however, he either was unresponsive or rejecting, asserting himself in a negative manner.

Quantitative analysis also showed this pattern of assertiveness and independence in 75% of all episodes of behaviors. LL's behaviors were, for the most part, unrelated to materials, to the environment, or to individuals. Twenty-five percent of his behaviors were coded as gross motor, and 30% were coded as affect. There was only one verbalization that could have been considered babbling. Interaction with materials represented 18% of LL's behaviors. Within this area 5% were passive behaviors, while 36% of his behaviors involved only simple manipulation. Those activities and tasks which LL completed successfully were at the level of a 12-month old child. What is even more distinctive about this child was that the number of interactions with materials was equal to the number of behaviors regarded as symptomatic, a highly unusual finding even in our atypical population.

Goals While on Program

The early projected goals were clearly reactive to the behavior observed during the first few weeks. They included "cuddling and body games to encourage warm human interaction" and activities which would lead to physical contact with other children. Elementary activities outlined in the other areas of development were encouragement of babbling, simple containment problems, and gross exploration of space.

Work with materials eventually included more difficult tasks such as removing spindles from a disc, putting a ball in a form box, and, much later, opening and closing a box. Eventually LL even became involved in simple water play.

The goals related to expressive communication also followed a clearly delineated sequence from imitative babbling to responding to requests of "Give it to me."

Evidence of continuing gains in physical therapy led the teachers to include periods of semi-independent ambulation, holding on to the rail, and opportunities for exploration on all fours.

The teachers continually tested the extent of LL's sensory awareness (i.e., materials that would provide auditory stimulation of one ear). Also included were various textures of fabrics and different colored plastic discs; these were offered to assess differentiated response patterns. Throughout all of LL's time in the program, there was a need for sensitive assessment and readjustment of goals. This process enabled the teaching staff to revise their understanding of this complex child and thus enabled them to achieve gains in several areas of development.

Progress Prior to Discharge

At the end of 3 months the Physical Therapy Department reported that LL was making dramatic gains. There was a strengthening of head and trunk control which allowed him to begin to crawl. Walking had also become more independent as a result of better balance. It was, therefore, decided to keep LL in the program for a minimum of another 4 weeks.

At the end of 4 months definite (although not dramatic) changes in LL's functioning were evident in all areas. Perhaps the most important to his family is reflected in the following statement: "Mrs. LL tried some things with him, but he complained and preferred her comfort." When he entered, he neither accepted comfort from adults or differentiated his mother as a particular individual.

His work with materials had also shown a differentiation in understanding (even if his goals for a task were often different from the teacher's). LL would spontaneously remove pegs from a peg board and spindles from a disc and then bang each of these on his teeth. He would do the same with a stick from a xylophone, after individually hitting each note. He also appeared to listen attentively as he dropped cubes individually into a tin can. Each of these activities seems to be an attempt to experience sound rather than to use the materials; they all suggested more organized exploration.

LL was now able to recognize his physical therapist, smiling when the therapist entered the room. LL also began to track objects when they left his sight; he would look down after throwing a cube purposefully off the table. The most dramatic evidence of an increased awareness of his environment was an incident in which LL returned to the shelf where his teacher had left some discs. When he couldn't reach them, he calmly pulled the shelf out. This, in his teacher's words, showed the beginning of problem solving and an "awareness".

LL also appeared to be more accepting of the presence of others (i.e., smiling when a teacher would come to his crib in the morning). He also began to accept the presence of the other children. Accompanying this change in social responsiveness was increased vocalization. This was in the form of babbling single vowels and consonants and usually accompanied social interactions.

To the delight of all, LL rarely kept up the persistent crying which had been ever present during the first 4 weeks. His affect had become much more appropriate -- crying in response to having a toy taken away, laughing and smiling in social situations and when he was pleased with himself and his accomplishments.

LL had become a much more independent child, able to maneuver himself around the room holding on to the handrails and the furniture. His independence was now reported in the form of his initiating an activity. It was only when presented with food that LL still exhibited a strong negative assertive behavior.

By the time of discharge there had been a marked change in the total picture of LL's functioning. One-fourth of all behaviors were now in the area of interaction with materials. Most of these still continued to include exploration of the materials, with 25% indicating successful completion of tasks at approximately the 12-month level. There was a decrease of 13% in those behaviors coded as affect with increase in interactions with materials, social responsiveness, communication, and gross motor activity. The most dramatic changes were an increase of 50% of active versus passive behaviors and a decrease of 80% in the total number of symptomatic behaviors. Thus, our general impression upon discharge was one of a child more actively engaged, aware, and responsive.

FINAL REPORT

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EVALUATION OF BEHAVIORAL CHANGE

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Part II:
Interaction Between Program and Parents

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Part II

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ABSTRACT

Part II: Interaction Between Program and Parents

Part II describes an analysis of open-ended, comparatively non-structured weekly interview sessions with the parents of the children studied in Part I. The primary analysis was qualitative from an anthropological perspective.

A conceptual model of reciprocity between program and parent was developed. Parent interaction was examined: what they expected from, gave to, and learned and used from the program. Reciprocally, what did the program expect from, give to, and learn from the parents?

Complementary quantitative analyses examined the parents' shift in focus from specific skills to a developmental orientation, their satisfaction with the program, and the degree of realism with which they assessed their children's status.

Most parents were found to shift from an original emphasis on physical and language disabilities to consideration of other dimensions of development. Both common and unique themes emerged from the analyses (e.g., separation problems, the effect of a handicapped child on parents and siblings, increased understanding of the use of appropriate educational materials, and need for support).

Parental satisfaction with programmatic intent and implementation was documented, as well as the change in parents from a passive and "recipient" role to one of greater spontaneity and participation.

Socioeconomic status and type and degree of disability of their children were not found to be related to parents' attitudes toward the program.

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STUDY OF THE INTERACTION PROCESS BETWEEN PROGRAM AND PARENTS

Introduction

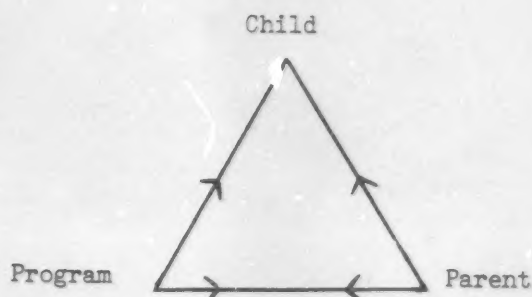
A prime component of the Infant Education Program at IRM is a strong Parent Program. A colleague from England stated: "It is no exaggeration to say that in the background of every individual handicapped child there is a handicapped family" (Sheridan, 1965, p. 100).

The parents in our program were both recipients and sources of information related to the developmental needs of their handicapped children. They met weekly with Prof. Gordon, the Project Director (P.D.), to exchange information related to changes in the child's development in school and at home. These sessions also provided an opportunity for parents to reveal the stresses, anxieties, and burdens of families with handicapped members. Problems were discussed that were directly related to the child's care and education and also those related to the effect of having a handicapped child on family relationships and on the social life of the parents. The parent component is thus in accord with the statement by Lane (1975) that: "Since parents are often aware of their own inadequacies, we can help by listening to parents expressing their own needs, frustrations, and satisfactions -- starting where the parents are... Parents must be involved in solving their own problems if any lasting solutions are to occur (emphasis added)" (pp. 5 and 6).

We have used tapes of these sessions (cassette taped with the consent of each parent) to extract information which revealed both the impact and effectiveness of the Infant Program on the lives on these families. The analysis carried out in this report stems from an anthropological perspective. Some of the issues raised are components of the conceptualization of reciprocity between the program and parents with respect to the education, therapy, and management of multi-handicapped children.

Figure 1

Model for the Interaction Process between Program and Parents



This reciprocity consisted of the following aspects:

Parents

1. What the parents expect from the program: Fulfillment of specific goals (such as walking, speech, etc.);
2. What the parents give to the program: Participation one day a week in the program; management, stimulation, and observation of their children over the weekend;
3. What the parents learn and carry away from the program: Specific techniques of stimulation, knowledge of learning disability, and age-appropriate materials.

Program

1. What the program expects from the parent: Participation one day a week, observations of children over weekends, learning of techniques of stimulation;
2. What the program gives to the parent: Evaluation and educational stimulation of children; interpretation of child's problems, progress, and character of program; specific guidance; and finally, emotional support;
3. What the program learns from the parent: Variations in the success with which parents have learned new ways of dealing with their children, causes of success and failure.

The range of information gleaned from these interviews is broader than material explored in most studies of parents of handicapped children. Those studies were either involved with (a) the impact of the birth of the handicapped child on the family and its long-term effects, (b) counseling the parents of handicapped children, or (c) parents' perception of their child's developmental level. The brief review of related literature which follows (integrated with the underlying philosophy of the Infant Program) illustrates why we have turned to a method of analysis based upon a model of reciprocity.

We do begin working with families while their children are quite young (the age range of children on program is 18 to 40 months), but it is obvious that the impact of the handicapped child on family life commences at birth. Several studies characterize the initial impact of the birth of a handicapped child as being one of anxiety, guilt, and rejection (Bentovim, 1972; Boles, 1959; Wolfensberger, 1967). Polansky, Boone, DeSaiz, and Sharlin (1971) characterized the parents' reaction to their impaired child as one of pseudo-stoicism. That is, the parents adjusted to their child's disability in such a way as to reduce their own depression and anxiety. Yet the authors indicated that these reactions "may also be found with normal children, if having the child was experienced by his mother as a psychological insult" (p. 649). Therefore, negativistic attitudes or feelings of anxiety are not unique to the parents of the handicapped child.

The attitudes of parents of handicapped children appear to shift as the child grows. The parents of children with cerebral palsy tended to become more overprotective as the children grew older. There was concurrent increase in marital conflict (Boles, 1959). Overprotectiveness was also found in the parents of mentally deficient children (Poznanski, 1975) and other physically handicapped children (Kogan & Tyler, 1973). From these and other studies it is evident that the most serious problem in families with handicapped children is not merely the handling of the initial crisis but also the long-range effects on family structure. The greater likelihood of stress was discussed by Boles (1959). In a study analyzing the families of children with cerebral palsy, the findings indicated that the more severe the disability, the less likely it was for a family to have additional children (Hall, 1963). The stress on mothers, fathers, and the total family structure, pointed to the necessity for early intervention with the family as well as with the child.

The role of counseling has conventionally been assumed by the child's pediatrician. Some authors believed that physicians do not adequately deal with parents' feelings, especially in terms of discovering why parents were unable to accept a diagnosis (Zuckerberg & Snow, 1968). This suggested that the "... need of parents of exceptional children is constructive professional counseling at various stages in the child's life" (p. 869).

Others associated poor counseling with the parents' basic inability for accurately perceiving their child's functioning (Matheny & Vernick, 1969). The extent to which parents of a handicapped child accurately estimated the child's developmental level and their expectations for the future was directly related to what they had already been told and how they interpreted this information. One attempt to test the accuracy of parents' perceptions of their children's functioning is found in a study by Wolfensberger and Kurtz (1971). Seventy-five percent of these parents of severely retarded children assessed their child's current IQ within 15 points. However, about two-thirds of the parents expected their child eventually to have a normal level of intelligence despite the current severity of retardation. One could then predict that parents would be more realistic in terms of present status than of future potential. A similarly unrealistic attitude in terms of overestimating children's current ability was found by Tew, Lawrence, and Samuel (1974) in parents of children with spina bifida. A study by Boles (1959) indicated that parents of children with cerebral palsy also did not accurately perceive their child's future potential.

A review of the literature on parents and their handicapped children revealed a wide variety of studies. Although these studies encompassed all phases in the life of the handicapped child -- from the initial impact of the birth of the child to long-range planning -- few have the broad scope of our program for parents. Sources of data were usually controlled studies on assessment of attitudes, values, and problems, exclusively using either questionnaires (Boles, 1959; Cook, 1963; Gumz & Gubrium, 1972; Marshall & Goldstein, 1970; Wolfensberger & Kurtz, 1971; Zuk, 1961) or structured interview sessions (Birenbaum, 1971; Evert & Green, 1957; Hall, 1963; Kleinberg & O'Connor, 1972; Koch, et al., 1959; Matheny & Vernick, 1969). Each of these methods produced valid results; the design of both questionnaires and interview, however, often affected the direction of the answers.

An exception to the above methods is the work of Shere (1971) with the parents of children with cerebral palsy. She related her experience with these parents through parent interviews, sessions of mother-child interaction, and in the use of lessons and guidance in working with their children. Underlying Shere's work was a premise similar to that expressed as part of the educational philosophy basic to our program: "Attention should be given to the holistic situation of a handicapped child whether one's goals are basically scientific, therapeutic, or both" (p. 59).

Our taped data are unique in content when they are compared to most previous work. We worked from open-ended, comparatively non-structured sessions. Each interview, therefore, differed in both content, quantity, and quality from session to session and from parent to parent. As with therapeutic work, the nature of a session varied from dealing with an immediate family crisis to long-term assessment of growth and development. Meetings with the parents encompassed all aspects of the child's life -- educational, medical, emotional, as well as consideration of the conditions prevailing in the parents' lives. The analysis which follows touches upon many of the themes outlined within the framework of a reciprocal interaction between parents' needs and an educational program.

This report focuses upon the following questions with regard to the families of handicapped children:*

1. To what extent does involvement in the Infant Program sensitize the families to the philosophy of the program (the individuation of needs of their multi-handicapped child)?
 - a. Do the parents learn to look at the development of the "whole child" and revise their initial goals correspondingly?
 - b. Do the parents develop the ability to select toys and activities appropriate to the child's manifest developmental status? Is this sensitization to the child's functioning a result of sessions with the Project Director or direct involvement in the therapeutic program?
 - c. With what frequency do parents actively participate in the Infant Program?
 - d. Do parents become equally involved in all phases of the child's therapy sessions? Are strategies, activities, and skills associated with disciplines other than education carried over into the home?
 - e. To what extent do other members of the family become involved in the Infant Program?

*Represents Part II of a two-part report; Part I reports the data on the children in the study.

2. Are there common themes which characterize one or another sessions with all parents? Are there themes characteristic of groups of parents? Finally, are certain themes peculiar to specific parents?
3. Do parents express the need for emotional support within the context of these sessions?
4. How realistic are the parents of children in the Infant Program? Can this be assessed from the parent sessions alone or is greater knowledge of individual parents needed?

Method

Subjects

The parents of the 40 children who had participated in the Infant Program each met with the P.D. for a weekly one-hour session. The extent of available data (more than 400 hours of tapes) led us to select 28 families for initial analysis. Twenty families were then selected for in-depth focus. Five families per year -- 1971, 1972, 1973, 1974 -- were selected, representing 50% of the families of the infant population studied ($N = 40$). Demographic data were reviewed and families were selected to represent a full range of variation of sex of child (13 male, 7 female), medical diagnosis (see Table 1a, Appendix I), socioeconomic status (see Table 1b, Appendix I), sum delay score, approximately half above a score of 10, approximately half below, (see Table 1c, Appendix I), and ethnicity (see Table 1b, Appendix I).

Table 2, Appendix I, presents a listing of the number of tapes analyzed for each family.

Procedures

Source of Data. Taped parent sessions were the major source of data for this study. These sessions were open-ended by design, loosely structured, guided by parents as well as by the P.D., unhurried, characterized by mutuality, i.e., the reciprocal nature of the interview process, and child-centered. Although occasionally parent-oriented to deal with parents' feelings, attitudes, and health problems, the sessions always returned to implications for the welfare of the child.

Emphases in interviews varied. There was spontaneous volunteering of topics and questions by parents, eliciting of comments from parents by the P.D., refocusing of parents' questions and concerns, and interpretations of children's behaviors, specific guidance as to what to do, and the provision of emotional support.

Throughout the child's in-patient stay, the P.D. and parents exchanged observations, congruent and incongruent, about the child at the Institute of Rehabilitation Medicine (IRM) and at home. During the final session, the parent and the P.D. recapitulated the experience, sharing their observations and comparing what the child was like at the beginning of his in-patient stay with his current status. It was at this time that post-discharge referral was planned, confirmed, or alternate resources offered for parental decision.

Method of Analysis of Tapes of Sessions with Parent. Over 400 hours of taped interviews between parents and the P.D. were collected during the period of the study. All tapes on the 20 parents who form the basis for in-depth analyses were transcribed and were extensively coded and annotated ($N = 191$ tapes). These tapes form the basis of the analysis to date. This has been supplemented by transcribed and annotated tapes on eight additional families. The transcripts were edited, and although editing "can never be a neutral act" (Fox, 1974, p. 6), we do not believe that the

content in any sense was altered. We believe the results are more readable and less repetitious and, at the same time, we have been able to safeguard the identity of the participating parents.

The data was analyzed both quantitatively and qualitatively. The primary analysis was qualitative. Themes of interaction -- common, variant, and rare -- were extracted. Attention was focused on episodes of an emotionally supportive nature. A qualitative analysis of the gradual sensitization of parents to the philosophy of the program was undertaken, complemented by quantified coding of the interaction process referred to below. Wherever appropriate, parents and the P.D. were quoted to illustrate a variety of generalized statements of findings.

The coding consisted of extensive annotations as well as classification on the basis of (a) source of statements, whether from parent or P.D.; (b) subject and content of statements related to the seven psychoeducational dimensions accepted as areas of potential change and growth (Interaction with Materials, Awareness of Environment, Social Responsiveness, Expressive Communications, Expression of Affect, Gross Motor Activity, and Fine Motor Activity); (c) context of statement, i.e., spontaneous or in response to the other speaker; and (d) quality of statements: positive, negative, or ambivalent.

A sample annotated transfer sheet for a session with Parent P is presented in Appendix I. The reliability of the coding system was studied by having a second member of the research team listen to complete taped interviews for parents O and X and code directly from them without the intermediate steps of transcription and annotation. The codings of both persons, which are presented in Tables 3a and 3b, Appendix I, are markedly similar.

Other kinds of quantitative analysis included: (1) the computation of frequency of participation in the program for the 20 parents; (2) a realism scale (averaging three methods--ratings, Q-Sort, and joint clinical judgment of the P.D. and the master teacher) to measure the degree of realism of parents as to the extent of their children's handicaps. Ratings and the Q-Sort were based on judgments made on all the statements derivable from transcribed sessions which bear on realism (see page 31); (3) a satisfaction scale, based on parents' perception of changes in their children's status and attitudes toward the program (see Item 1, Appendix II). All statements in the sessions bearing on satisfaction were scored and averaged for each parent. The scoring was carried out by two persons and a reliability coefficient derived; (4) a satisfaction questionnaire (see Item 2, Appendix II) was mailed to parents in May of 1975, seeking their reactions to the program, the child's progress, and their attitudes as to the value of interviews with the P.D. The interval between receipt of the questionnaire and the child's discharge from the Infant Program varied from 5 months to 4 years.

Results

1. To what extent does involvement in the Infant Program sensitize the families to the philosophy of the program (the individual needs of their multi-handicapped child)?

Parents' abilities as observers of their children's behavior should not be slighted. A number of parents were sharp observers of their children's problems and progress.

This role was realized to a maximal degree by parent H. Throughout an interview sequence of 5 months' duration, Mrs. H gave a detailed description of the child's activities, evolving differentiation of people, development of separation anxiety, favorite toys, communication behavior, environmental awareness, social responsiveness, self-assertion, feeding behavior, etc. Indeed, the description of the child's incipient sitting behavior occupies one-half page of a transcribed interview, and there was also an extremely detailed narrative of his later crawling behavior. Her sensitivity to the most minimal change in this very severely impaired child (psycho-motor retardation) was epitomized in a statement during an interview in the course of the second month of the child's in-patient stay that "... every week he tried to do something new that really surprised us..."

Another example of a mother's increased awareness of subtle changes in her son's abilities is illustrated in this statement by Mrs. LL:

"He takes cookies out of the cookie jar. He never used to do that before... I was really shocked... I thought that maybe here he was just doing that, but at home, too...."

Evolving sensitization to observations of the child's behavior is also illustrated in this quote taken from the final interview with Mrs. JJ:

"I know he understands whatever I told him. Before I didn't think he really understood. So now I know how much he understands. I can work with him a lot better... he's sitting a lot better... his head (head control) to me is almost 100%."

The following quotation from the father of Child U offers a sample of the way in which parents conceive of their changing perception and behavior while participating in the program:

"I was thinking how my attitudes have changed in dealing with U... Before I tended to look slightly stoically at my time with U. It may not work... There was a certain amount of gesturing on my part with U. (We know from previous interviews with Mrs. U that her husband put objects in his mouth to stimulate his child to do likewise or amuse her.) Now I have a changed perspective... U really can learn things if it is at the same time taught to us. It isn't haphazard, catch-onto something."

a. Do parents learn to look at their child holistically and revise their goals correspondingly?

There is evidence of a shift in parents' focus and attention to their child's functioning during the time their children were involved with the Infant Program. In terms of quantitative analysis there was clear evidence of a shift in emphasis and content during the time children were on program. After each series of parent sessions had been transcribed, coded, and transferred to data sheets, the codings were tallied for each family and for each dimension. Interviews were then grouped together to correspond with the child's time periods. Percentages for each coding category were derived.

At the beginning of the child's stay, the concern of most parents was centered on overt malfunction in motor areas and/or on absence of or paucity of expressive language. (Only one family did not delineate any goals at the initial session.)

Sixty percent ($N = 12$) of parents stated the motoric as the major goal, and 10% ($N = 2$) stressed it as a secondary focus. Thus, 70% of parents emphasized this area of functioning.

Fifteen percent ($N = 3$) of parents stressed expressive language (speech) as their focal concern, and 25% ($N = 5$) stated that speech was an important, though not primary, goal. Thus, 40% of the parents were aware of speech disability in their children.

Individual parents mentioned respectively as a major focus of concern: environmental awareness, social responsiveness, affect, sensory problems, and the quality of play (an upper SES* parent). Only one parent (upper SES and an educator by profession) stressed all areas of functioning equally.

One major program goal in our interactions with parents was to shift their focus on one fixed and specific aspect of development to a greater understanding of the child's overall developmental status -- physical, cognitive, social, and emotional. The interactive quality of these parameters of development was explained to the parents and stressed. After time spent in the program there was a tendency for parents (14 of 20) to focus less on motoric functioning and to focus more on interaction with materials (15 of 20). Table 4, Appendix I, presents a sample of tabulated data on parents of children J and P, illustrating their shift in focus to the other aspects of their child's functioning.

It had been hypothesized that parents would demonstrate increased valuation of their child in the course of their child's stay. The statements of 85% ($N = 17$) of the parents became increasingly more positive about their children across all seven dimensions of functioning. This increased positive view by parents of their child is illustrated graphically for two sample families, J and P, in Figures 1 and 2, Appendix I.

For parents J and P (as with the other families studied), interviews in the final time period (just prior to the child's discharge) did not fully reflect the trends which had emerged up to that point. We associated this "plateauing" or change of slope during this time period with the intended

* Socioeconomic status

change of purpose and focus of the final interview session. The "final" meeting had been clearly established as a review by the P.D. It was described to the parent as a summation of the preceding months of the child on program.

The staff, including the P.D., attempted to offer a realistic view of expected outcome in a short-term, in-patient program. Mrs. H's statement verifies her understanding of the program limitations:

"When I first came, Dr. G. gave me a rough idea: 'We'll work with him and see what we can do.' Miss M. (social worker) explained. She speaks very slow... so I asked her everything and they explained everything and I understand right away... and I called my husband and I explained everything and he understood right away... and then I came to you and you explained everything to me -- not to expect miracles -- and I said: 'You know, we weren't expecting...'"

Thirteen of the 20 parents whose data were examined demonstrated an increase in spontaneous comments. This finding may be interpreted by the parents' increase in (a) their understanding of the program and valuation of the child, (b) their comfort with the P.D. and interview procedures, and (c) their self-valuation as valid observers and recorders of differentiated performance. This finding may also be interpreted as the product of successful "enculturation" of the parents to educational goals observed directly during participation in the program and/or as translated by the P.D. and teachers. (Table 5, Appendix I, presents quantitative data on 20 parents.)

b. Do the parents develop the ability to select toys and activities appropriate to the child's manifest developmental status? Is this sensitization to the child's functioning a result of the sessions with the P.D. and/or the result of direct involvement in the therapeutic program?

There is evidence that, as a result of both active participation in the educational program and meetings with the P.D., parents became better able to select toys and activities corresponding to their child's current developmental status. Educational stimulation of the child by the parents and the buying of appropriate toys were discussed at length with several parents.

Mrs. F:

"I think that I learned a lot from this project... as far as the kinds of materials to buy -- what's structured, what isn't. We had nothing like that. Now that's all we look for, and we can see what they're learning on these different things. Before it was just a toy. I learned from Mrs. B. Now I'm more aware. His little brother has even benefited." (Note the extension of parental learning to the handling of the impaired child's sibling.)

Mrs. II, toward the mid-point of the child's in-patient stay, spontaneously brings up the subject of toys, remarking that she had the wrong sort of toys at home and wanted to buy her son more suitable play materials. The

P.D. offers to go over the catalogue of educational toys and advises Mrs. II where to buy them. She also advises Mrs. II to tell the grandparents the kind of toys they should give when an occasion calls for a present to the child.

Mrs. X also became aware of the importance of the right kind of toys for a child:

"I know how to select toys better... he understands colors, shapes, and knows what to do with them. I understand the purpose of the toys: discrimination."

Mrs. C declared that her main purpose, when the child comes home again, is to play with educational toys. The P.D., as she always does when the parents spontaneously bring up the subject of toys, offered help in selection.

Parents, especially those with limited means, were advised to improvise materials at home (such as making play dough out of flour, salt, and water, using pans to teach the containment concept), to borrow materials from the Infant Room "toy library" for the weekend, etc.

c. With what frequency do parents actively participate in the Infant Program?

The parents were informed in no uncertain terms that they were expected to participate one day per week in the program, to observe the teachers and therapists, and to apply what they had learned at home during weekends, while the children are in-patients at IRM and after the children are discharged. Few problems emerged with respect to the weekend requirements. Only one or two parents were unable to comply fully.

Records were kept of the participation of parents in the Infant Program. The P.D. in the initial interview communicated to parents the expectation that they would participate in their children's program as observers and co-teachers. In addition to the dates of interviews with the P.D., we have records of dates of actual involvement by parents in the Infant Program, providing a more complete documentation of the parents' patterns of participation.

From data of parent-P.D. interviews and teachers' records of parent participation, the families studied fall into four groups. Of the 20 families examined, four parents attended, participated, and were interviewed every week of the child's stay in the program -- in effect, 100% participation. Seven parents fall into an 86 - 99 percentile, seven into a 66 - 85 percentile, and two under the 66th percentile.

Figure 2

Percent of Parent Participation



The four parents (20%) who participated maximally (100% of the time allotted to them) were middle to upper SES, but it was not obvious in what ways they were really different from parents with a slightly lower level of participation.

Attempts to enculturate the parents into the spirit of participation and learning were not always successful. Parent II is a case in point, representing only a middle level of participation. Mid-way in the child's inpatient stay of the program, the P.D. emphasized the crucial importance of the educational program and asked Mrs. II to ask her older daughters to carry out the program's educational techniques at home.

P.D.:

"It's terribly important that you watch and work with the teacher, because II is starting to do things that show us that he can think."

It is suggested that Mrs. II come early in the morning (she had often been late) because that is when the children are more alert. At the end of the interview, the P.D. again encourages Mrs. II to observe the educational part of the program.

With parent B, who had the lowest level of participation (she did not visit nor get involved in the program, nor even take her child home on most weekends), an attempt was made to encourage this passive Spanish-speaking mother, for whom there existed a cultural and language gap, to increase her participation. First, the P.D. explained the importance of having the child spend weekends at home. She offered help in the form of taxi fare reimbursement, payment of a babysitter for siblings, and changing the day of participation. Finally the norm was emphasized by stating that other parents come, thus implying that Mrs. B was deviating from the behavior appropriate to participants who have children in the program.

Perhaps as strong a formulation as any by the P.D. which speaks of her attempt to enculturate the parent to the latter's role of participant and learner is the following to Mrs. JJ in the initial interview:

"... one of the reasons we want parents to come and spend the day with us is that, if you see what we are doing, if you can carry it out at home, you have the best chance of success.... If the child doesn't know (common) expectations... he expects one thing at home, another thing at the hospital, and so he doesn't retain what he has learned during the week. You lose two days of the week when he could be doing what he has learned to do."

d. Do parents become equally involved in all phases of the child's therapy sessions? Are the strategies, skills, and activities associated with disciplines other than education carried over into the home?

At least five parents were strongly involved with the physical therapy that their children received. Thus, Mrs. N kept an appointment with the physical therapist made by the P.D. in order to be taught how to put braces on her daughter. Mrs. DD spoke to the physical therapist and was taught how to exercise her son. Mrs. X also had an appointment made by the P.D. to see what kind of exercises the physical therapist was doing with her child. In her final interview, Mrs. P said that she had learned stretching exercises in physical therapy which she would practice at home.

A thread centered on physical therapy ran through most of the interviews with Mrs. H. Towards the mid-point of the sequence of interviews, Mrs. H reported that her husband for the first time saw progress and that he was impressed with the work done by physical therapy. She had bought him a movie camera so that he could shoot some film of the P.T. exercises. "So I feel I have at least a few things on film to remind myself exactly what I want to do," she says.

Language stimulation also observed by parents at IRM was often carried over into the home environment. Thus, parent H reported:

"My husband said, 'Come to Daddy.' I say, 'Come to Mommy, make nice to Mommy.' But still he says 'momma,' 'dadda' to the doctor. We're still trying to see if we can get him to tell the difference."

e. To what extent do other members of the family become involved in the Infant Program?

We possess only sparse data on sibling ties to the child. They run along a continuum from withdrawal (family N); missing the child (siblings of child B); asking questions about when the child will be able to walk (sister of child C); visiting her brother at IRM with her mother (family A); reporting on progress of child (siblings of child J); holding off a birthday party until her brother came home for the weekend (sibling of child H); and not going away for a weekend, as the only time she saw her brother was then and she felt she should devote all her time to him; even to doing physical and language stimulation with the child (older sibling of child LL).

One sibling's involvement with both her brother and the Infant Program was dramatized by Mrs. H's statement:

"His sister says, 'We have a real baby now, a real baby that sits, a sitting baby.' Because all the other babies are sitting and standing and her baby isn't, she thinks maybe it wasn't a real baby... She's so excited, she's telling everybody. They stick together, they watch TV together. She said: 'I could have kissed him, I was so happy. Mommy, that hospital is good. If anything should ever happen, Mommy, if I should ever get sick, I want to go.'"

Mr. and Mrs. H were delighted at their daughter's attitude when she suggested postponing her birthday party until her brother is at home. "We're glad she thinks this. She includes him in everything. Friday evening she can't wait for Daddy to bring him home." Family H is obviously a closely cohesive family. Mrs. H, who is the parent interviewed by the P.D., was constantly saying, "My husband said..." thus indicating close communication and implying great marital harmony. Their daughter is also closely identified with the child and with her parents.

In both families C and II, siblings of the impaired child were taught by the mothers or have watched physical therapy and speech and hearing therapy, and they put their learning into practice. Thus, Mrs. C says, "My daughter is trying to teach him new words. She has seen them doing this."

Mrs. II reports that the sisters of the child watched the master teacher, Mrs. B., and spoke to the speech therapist to learn about speech stimulation. The mother was encouraged by their interest. She said, "The girls can label things at home." In a later interview, Mrs. II stated that the girls were watching the speech therapist, especially the oldest daughter who got along best with her brother, in order to learn how to stimulate the child at home. It should be remembered that the language area was very important to Mrs. II who, in the very first interview, mentioned speech as a major concern and shifted to the topic of speech when the P.D. talked about interaction with materials in one specific interview.

Some upper SES parents, with the help of babysitters and housekeepers (family N and family U) were able to be involved in observation of the general developmental program, including physical therapy and language stimulation. The assumption was that they would try to incorporate the new techniques at home, after discharge of the child.

2: Are there common themes which run throughout all the tapes of the parent sessions? Are there themes characteristics of groups of parents? Are there unique themes?

We teased out the major themes, both commonalities and variations, across parent groups and sequentially for each parent. There were certain constants in the evolution of parent interviews. Some questions asked by the P.D. reoccurred, as did questions asked by parents. Some responses or statements made by the P.D. and parents also varied little as to content, e.g., information transmitted about improvement in functioning of a child.

Some themes, which appeared constant from parent to parent in the interview tapes transcribed, follow:

a. Separation anxiety of child and parent -- Separation anxiety of child and parent occurred universally in our population, both as fact and as concern and topic of conversation between parents and the P.D. Examples follow indicating the P.D.'s interpretation of separation problems which were worry and pain for the parent and which were normal and positive reactions for the child.

Parent II:

"He cries when I leave him."

P.D.:

"Normal. If he didn't cry, I'd be worried. He wouldn't be separating his feelings about his mother from other people. It's a good sign of his emotional involvement with you. That's a plus. It's hard for you. As he gets involved with play activities and gets more comfortable with us, he won't fuss as much. Activity becomes more important than home... Part of the child's security is that the mother comes back. This will make him more trusting of you and of us and more open to work with us because, if he's anxious, you can't get him to work."

To parent X, the P.D. said:

"Don't be upset by his anger; he cares about you when he makes a scene."

Parent X:

"I know that, but I don't like to see it."

Parents F bring up several times the problem of separation anxiety, and the P.D. responded:

"If it's too much for him, we wouldn't keep him in the program."

Mr. F:

"He will not be productive because he misses us so much."

Mrs. B. (master teacher):

"It's better that he misses you." Is the child asleep when you or the grandparents leave?"

Mr. F:

"Yes, he's asleep."

Mrs. B.:

"I think it would be hard for you to say good-bye. He's going to have to learn that you're coming back... you wouldn't want him not to miss you.... It's better that he misses you."

P.D.:

"I worry about a child who comes in here and is content. It means that the child makes no connection with home. And there'll be a point when you take him home on weekends. I suspect that when you bring him back that he's going to cry. And that's good. He's saying, 'I recognize the true situation.' Then there also will come a point in time when the child is perfectly happy to come back saying, 'This place is more fun for me than home.' It is, in some ways, because there are three other kids with whom to play which you can't provide, plus hours of constant activity... There is a kind of pattern. First kids don't want to come back, then they're perfectly happy to come back. And you can't predict when it happens, but it goes somewhat like that with most of the children."

b. Temporary regressions of the child at home over the weekends or upon parents' participation day -- Regression of the child is also a universal fact and topic of conversation. It is closely bound up with the preceding category, e.g., tensions associated with separation anxiety.

Examples abound of regression in the child's behavior when the parents visit or after the weekend at home. Witness the following examples in which the P.D. interpreted what appeared to be inexplicable regressions of the child.

Mrs. K:

"I'm so excited. This Friday I saw much more. Last week he wouldn't walk because I was there."

P.D.:

"When you're here he's still stays involved with other interests. It becomes a sort of cycle. The first month children don't work when their mothers visit. The second month they start to work when the parents are here. And then there is a kind of transfer of attachment. By the third month some parents are jealous because the kids become so attached to the teachers."

To parent DD, who reported that the feeding problem was worse on the day she was here, the P.D. replied:

"He fusses more when you come, but many children do this to make it hard for the parents...."

The same parent in another interview reported mouthing behavior at home, and the P.D. commented that she saw less of this at IRM. When Mrs. DD spoke of the child's making a fuss when a stranger came to the house, the P.D. responded, "The child is differentiating people -- those he knows and trusts from strangers."

Another interpretation is provided of the cranky behavior of a child when the mother visited in the afternoon.

P.D.:

"For little children the late afternoon is a difficult time. They're tired and cranky after a long day."

More serious regressions occurred when a child who was on program was subsequently hospitalized for medical reasons. This was the case with child K and was explained by the P.D. in the following terms: "This comes out as a thumb in his mouth and not being willing to work." This is interpreted as a return to more infantile behavior.

c. Value of a peer group for children in the Infant Room -- The immense value of the peer group of children in the Infant Room as a catalyst for growth was mentioned frequently by parents and the P.D. To parent JJ the P.D. commented:

"Children always motivate each other. If one child sees another one playing with a toy, he'll watch that other child, but eventually he's going to want to do it."

To Mr. DD the P.D. emphasized the value of the peer group as a stimulant to speech development:

"Children copy each other. Putting the child in the right place at the right time brings the child suddenly to do things that he was not doing before."

Concerning fighting behavior and possessiveness, the P.D. said to Mrs. N:

"They care about each other, are interested in each other... Fighting, grabbing of things is very important. Two or three of them are pulling things, they're interrelating. We (adults) can't do this with children, but they can do it to each other. And they start learning what I can take and what I can't and what happens when I reach for something that isn't mine."

Mrs. II:

"He seems to be quite happy with everybody about him."

P.D.:

He's enjoying himself. He likes the children. It's almost like a little family. They all help each other do different things, watch each other, and so learn from each other."

The significance of the peer group was especially well brought out in several of 15 interviews with parents U. For example, the P.D. pointed out:

"One thing we have found in so many youngsters is the value of a chance to interact with peers, even on the most primitive level -- touching."

Mrs. U:

"I was a witness to N and U's playing in the same water. Fantastic."

P.D.:

"Typically young behavior."

Mrs. U:

"... N walked to get to U."

P.D.:

"... the interaction of children, I agree with you, is terribly critical.... T said to U, 'Don't cry.' You can't teach this in speech therapy. You need a feeling, an empathy.... (This) caused T to put his words together... this is where you get more of your motivation to develop language. When something becomes important enough for U, she will want to express it."

In the eighth interview, the P.D. said:

"T played so well with U and L, too. I think U is very attractive to little children -- her hair, the blondness."

Mrs. U:

"R is not interested at the moment. R is so involved with his own world."

P.D.:

"They act as marvelous catalysts for each other, even though they don't have joint play in its true sense. They begin to establish a connection. Here is another child."

Mrs. U:

"U has always been interested in other children."

d. Development of self-assertion in the child -- Self-assertion was defined by the P.D. in response to parents' complaints about their children's strong wills, tempers, anger, or difficult behavior. It was

a topic which came up in almost all interview sequences with parents, usually in the second or third interview.

This was the case with Mrs. KK. The P.D. interpreted the child's new anger as follows:

"He'll get angry at some point. He'll want something another child has. If II decides he wants what KK has, he'll reach out and pull it. KK should get angry. And then he screams and hits out. That's the right behavior for that kind of situation. So, sometimes, things that look negative are very appropriate for little kids."

To Mrs. KK in the final interview, the P.D. stressed the significance of self-assertion and self-direction (initiative) in the following words:

"You know, nothing is quite as positive as when he initiates something himself, because it means, 'I want to do it.' This is much more meaningful to me, as an educator, than when someone says, 'Do it,' or 'Practice this.' He is showing a very clear decision, 'I don't like that. I want this.'"

e. Assumptions of parents about their child's current and future status -- Most parents' assumptions as to what the program could do to help their children were amorphous. Many parents tried not to hope too much for fear of disappointment (e.g., parents A, H, and II).

Guarded expectations were expressed by Mrs. H as follows:

"You know, I said to my husband, that if H can come to recognize us and really be aware of what's happening, sure, we'd be very happy. But we're not expecting it to a point that if it doesn't happen we'll be disappointed that we decided to bring him here... everybody's trying their best and working hard, and if progress comes either now or later, we'll be happy, but you know, it's just one of those things. Everybody said to you, 'Go all the way to New York... couldn't you find a place closer?' But we want the best... we look for the best for him... the problem is here that if he can get over it, sure, we'd be very happy; we're not expecting... and we know how slow he is, so if anything is going to happen, it mightn't be overnight; it's going to take a while. We've waited this long, two years; we'll wait and we'll wait."

Obviously, parents wished for some kind of progress, most often in the motoric area; some also stressed communication, and a tiny minority wanted improvement in structured play activities, as parents C and U did, for whom the coordination aspect of play was primary (although the cognitive implications escaped them). Few parents initially spoke of the emotional and social development of their children per se, the quality of interpersonal relationships, or the importance of peer relationships, although they may have been concerned with the flat affect, non-differentiation of people in the children's lives, and especially the apparent lack of attachment of their children to themselves (which in the course of the in-patient stay of the

child would develop as a result of commitment by staff for interpersonal involvement).

Realistic attitudes were encountered in some parents. For example, Mr. T expressed the following in the first meeting with the P.D.:

"The child is kind of slow... a 2-year old should walk... language is delayed."

Parent U:

"You don't really expect U to say any words..." (which attitude was later confirmed).

At times, as in an interview in which unrealistic attitudes were also expressed, the P.D. had to help Mrs. U to a more realistic notion that her child had not changed completely. She expressed the reality cogently:

"I just don't want you to become unrealistic. I don't want you to be hurt. There's a spurt of growth, of gains, and we'll build on it, but let's not reach for the sky. I don't want you to believe that we're going to turn a child with problems into a child without problems."

f. Parents' concern about the child after discharge -- The child's status at discharge was discussed at length during the last one or two interviews. Follow-up plans were discussed then and were often a re-iteration and expansion of plans made earlier in the child's in-patient stay.

In the case of child KK three weeks before discharge, the parent was encouraged by the P.D. to visit a neighborhood program to see whether it was conveniently situated. (At this point KK's mother objected to having the child discharged so soon. She was reassured that the child could be on program a few weeks longer since he was still in the process of making gains.) At the very beginning of the final interview (after her visit to the new center), Mrs. KK indicated that she was pleased with the center's 5-day-a-week schedule, but she complained bitterly about the teacher-children ratio (one teacher and one teacher's aide for 10 children). The P.D. did not fail to point out to Mrs. KK that few agencies exist which would provide the teacher-child ratio to which she had become accustomed at IPM (one teacher to two children). In addition, Mrs. KK was disturbed by the absence of a parent participation component in the new program. How could she carry out the program at home if she were not allowed to watch it at the center, she complained!

There were mixed feelings on the part of some parents and their relatives about the impending discharge of the child. Thus, Mrs. H:

"My sister said, 'He's doing so well, they should keep him a year.' I said, 'No. I'm grateful he's going to come home now.' She said, 'They did so well in 4 months; can you imagine what they'd do in a year!' And daddy says, 'And when he comes home, he won't even know us.' And we want to get back to the normal routine now."

Themes which vary from family to family -- There were a multitude of themes which varied from parent to parent, such as the effects of the child on family milieu (cohesiveness, conflict, etc.), the relationship of family with neighbors and friends, invidious comparisons by the parent of one child with other children in favor of her own child's status, problems engendered for the child in a bilingual home and with peers, etc.

a. The effect of the handicapped child on the family milieu -- In the case of Mrs. N there was the tendency for her to withdraw from involvement with her daughter, for fear of being unable to manage and keep up her facade. Mrs. N's attitude is the more poignant as the child was born normal and developed a brain tumor at five months of age. Mrs. N was concerned about the withdrawal behavior of a young teenage sibling of the child and the "unrealistic attitude and behavior of my husband." She went on to say:

"My son is strong, but I've watched him withdraw from the situation already, although he plays with her. There's a decrease in personal contact. This is the male role. They can't... men -- possibly my husband -- are unrealistic because they can't project...."

P.D.:

"Fathers appear to be less able to take a child who is disabled."

A month later Mrs. N appeared to be disturbed by the behavior of her three teenage children.

"I was discussing this with my husband last night how the children were detached, hands off. I told them to watch her and she was dumped back into the playpen. All kinds of excuses as to why she (older sister) couldn't feed her.... What's behind it is a wish that we could go back to the days when we didn't have her. I imagine that's certainly on everybody's mind. That's normal."

Mrs. N was dissatisfied with her husband's undemanding expectations of their handicapped child and his faith in Mrs. N's ability to right the child's condition, if she works hard enough with her.

"He's so undemanding of her, accepting of N... he's reached a higher level of acceptance than I have... he's placed strong responsibility with the children on me. He feels today our other daughter is as she is primarily because of my efforts. People would doubt that N would change. And my husband said: 'If F. works with her, she'll be fine.' I would cringe inside and say, 'Please don't ever do that to me. I don't want the praise, just as I don't want the blame.' I couldn't take that kind of responsibility. His feelings are that as long as I keep plugging and teaching N, as long as I never give up and he supplies the funds, between the two of us he doesn't think we'll make her normal, but we'll take her as far as she can go...."

P.D.:

"That's a burden."

Mrs. N:

"Tremendous responsibility. If I said a school in Paris could help her, he would knock his brains out because... that's how he gets out of it. That's his cop-out."

P.D.:

"It must be rough on you."

Mrs. N:

"My husband is not program-oriented. He's family oriented. His frame of reference is himself... he lives in this 'I will do it' frame of reference...."

Mrs. N also faced the problem of how to balance the needs of her other children with those of N. Thus, she was highly ambivalent about the kind of Bar Mitzvah one son would have were it not for N's handicap; yet, she didn't want this teenage son to be penalized by his sister's condition. She said:

"We made plans. I mentioned to Dr. G. that my son's Bar Mitzvah was coming up. I envisioned N carrying on and the whole bit, and I don't want to go through a big shindig, which I consider in bad taste. But we don't want to deprive him."

For family H there appeared to be acceptance of the child by both parents and joint involvement in his education and care. The father's involvement with the child over the weekends was especially stressed by Mrs. H:

"One day of the weekend (when the father does not work) is devoted to H, and he brings all the toys and he puts everything in the tub. He gets everything ready and he really works with him."

The state of the household and housekeeping over the weekend reflected the centrality of the efforts of the H family to stimulate their child in all manner and by all means. Mrs. H said:

"You should see what the apartment looks like when H comes home. It's such a mess. I said to my husband, 'Anybody who comes in who can't understand, it's too bad.' Because everything is out. We have him on the floor and we have the table and everything."

Mr. H:

"Everybody knows when H is in town. I'm telling you, you have to step over things, everything is out."

The desire for physical closeness and affection was underscored by Mr. H's refusal to interact with his son in a wheel chair. Mrs. H reported that "he wants to hold him, feel him." She commented about her husband's involvement, "What his daddy tried to do with him is terrific." She reported in a later interview, close to discharge time, that her husband did some painting in the house every day after work. When she asked him why so late, he answered, "When H comes home, we shouldn't have anything to do. We want to spend all the time with him." Mrs. H responded, "Right."

Father LL was also capable of deep involvement with his son through his particular form of play, rough-housing:

"I play with him rough -like. If I catch him in a good mood, he'll do just about anything. I can't be soft."

P.D.:

"Do it as it is comfortable to you."

Mr. LL:

"It doesn't make any difference as long as he makes me laugh and I make him laugh. He's responding. We make noises together, play peek-a-boo...."

The P.D. emphasized the importance of grandparents, other relatives, neighbors, and friends in their capacities to confirm or validate changes as the child progressed in his in-patient stay. They may also serve as potential support -- both practical and emotional -- for parents, especially working parents. The P.D. thus suggested to various parents that grandparents be encouraged to come and watch the program so they in turn could duplicate the teaching at home. The effect of these people (relatives) in the social network of parents was, however, often negative, sometimes markedly, either in their denial that the child was impaired or in their doubt of the effectiveness of IRM to remedy any impairment.

Mrs. C:

"The grandparents think there's really nothing wrong. Why is he at IRM?"

Mr. F:

"Can we have a picture (of the psychologist with the child) to show the grandparents that he enjoys himself. It might help talking to them. They feel we can do better with him at home."

Mrs. F:

"My husband's mother is counting the days until he is discharged, despite my husband's trying to persuade her that he's being helped here..."

A qualified attitude was expressed by Mrs. N:

"My mother can face the problem of N. My father thinks that one day she is going to wake up. So I don't want them coming here and seeing the other children. They wouldn't have the time to develop any other attitude...."

In a later interview Mrs. N, when considering a trip for her family -- herself, husband, and children -- abroad, felt she was able to depend on her mother:

"... maybe my mother will be here... and if she can be led straight into the room and led straight out again, it will be O.K., because she does a lot of work with this child. My mother is very patient and she's taught N many, many things.... If she comes, she's the one who will watch intently to learn and work with her, because she always has."

In the initial interview Mr. T complained about his mother spoiling her grandson and fostering dependency. He said: "Like she tends to cater to his needs all the time." The P.D. reassured the father that, "It's not only your mother, it's every grandparent...." She continued:

"The important thing is he won't benefit from our being over-indulgent... we'll see how long he can take frustration, not too much, not more than a child can handle... but I think if your mother sees that he's getting more independent, she'll be pleased with that, too, and then, if she sees the results, she'll be able to accept it."

At the end of the fifth interview, the P.D. suggested that Mr. T act as interpreter for his mother of the interaction with materials of which the child was capable:

"Things that are important for his growth... she is the one who feeds him and takes good care of him physically; there's this other part of his development which is important."

In the sixth interview the P.D. asked:

"How does your mother feel about T? Does she see changes in him?"

Mr. T:

"I've just been explaining to her what T is doing here. I don't think she's been aware of the significance of this institutional life. She would just like T to get up and walk right away, just like that, without any trouble."

P.D.:

"We have to get her to understand the medical problem involved in his walking... that it's not just a question that he's a little slow, that he's had some change in his development compared with other children. Do you think she doesn't want to understand it or do you think that she is really trying to face it with you or is she more comfortable pretending it doesn't exist?"

Mr. T:

"I think she feels more comfortable to think it doesn't exist. She feels that at any moment T can just get up and start walking. She's talked about a couple of dreams she's had; she sees T walking."

P.D.:

"It's wishful thinking, it's understandable. You wish hard enough, you may think it might come true, and I guess...."

Mr. T:

"I know that it's just not overnight...."

During the course of the seventh interview the P.D. suggested again to Mr. T that he bring his mother into the program, to which Mr. T replied that he would do his best. (The grandmother eventually did come to visit and observe.)

One grandmother, mother-in-law of Mrs. LL, was the only grandparent in our sample of 20 families who actually participated in an interview with the P.D. She remarked:

"There is a tremendous change. He's alert, he remembers the family now. I see him on weekends."

Thus, with an exception or two, anxiety and fear associated with seeing the sights of IRM, denial of the problem with their own grandchild, and family centeredness, as far as correcting any problem was concerned, were the factors which rendered the grandparents less than useful in supporting the parents psychologically (that they made the right decision in bringing their child to IRM) and in aiding them at home through educational stimulation of their grandchildren.

b. Effect of handicapped child on the quality of social life of parents -- Leisure patterns of some parents with respect to their relatives or other persons and places were affected in the direction of withdrawal from contact and toward isolation. Mrs. H said:

"Over the weekend we're really doing a lot with him... my husband doesn't want to go visiting my sister. He says, 'Let's stay in the house where we can really use these things and help him.' So we stay home and my sister visits and we don't have to go out of the house. We stay home and she visits. We don't have too many friends, so we don't have to go out of the house -- we stay home. Like teaching him with the water and everything. My daughter puts little toys in the water and he reaches for them."

Mr. A declared:

"We don't go no place since he was born."

Mrs. II erected walls around her family:

"If you don't bother me, I don't bother you. I'm home. I don't visit nobody, nobody visits me, except if one child is ill. I just stay inside with the family... I was kind of brought up that way...."

Yet she qualified her favorable attitude toward the state of isolation by adding, "(but) there are times when you need somebody."

Occasionally neighbors and friends were appreciated for the validation of changes in the child which they provided. (Mrs. C reported that neighbors saw an increase in the child's vocabulary.) Occasionally neighbors were perceived as intruders. Thus, single parent X wanted "a new start for him (the child) and herself." She was planning a trip to the South and then a change of apartment and neighborhood because "the neighbors are too nosy" (about the child's condition). A whole episode developed around the sensitivity of Mrs. X to neighbors' curiosity and questions, in which the P.D. tried to make the parent realize that questions would always be asked and that both she and her son (when he's older) would have to cope with these unavoidable invasions of their privacy.

One parent, Mrs. N, alluded to neighbors' (rather than the family's) withdrawal from, or at any rate, ambivalence about, interaction:

"Neighbors with children kept away from us and this time I saw a mother come out with her child. N had a reaction to this child. Awareness of the child. Nobody had brought their children until this time. I called the mother to come over. 'How do you enjoy your normal child in the presence of a child who's got problems?' But she was curious. It was an open situation."

c. Problem of bilingual home for the multi-handicapped child -- Mrs. K and Mrs. V have bilingual homes. This is considered to be a problem by the P.D., the educational staff, and other staff members (Speech Department), who feel that multi-handicapped children with neurological disorders have enough of a problem learning to speak English without compounding matters with a second language. Thus, although Mrs. V tried to stimulate her child linguistically, she used Spanish as her medium. Her husband and son usually spoke English to the child. It was suggested that English be used as much as possible but that Spanish was certainly all right in intimate emotional situations. Mrs. V was encouraged to go to school to learn English. (Apparently Mrs. V only needed to know Spanish for her job.) "So that you can increase your vocabulary as your children are increasing theirs," the P.D. concluded. In an aside she remarked that men are forced to learn English (presumably for the sake of their jobs) but not mothers.

As perceived by the P.D., there may also be a bilingual problem for child K at home:

"How much is a bilingual problem, when your husband speaks Spanish, you speak English, the neighborhood is Spanish... how much is confusion... how much is related to his (neurological) condition... C. (youngest and normal child) is our test for this in a sense. We'll see if C. picks up English."

The P.D. was concerned by the fact that only Spanish-speaking neighbors take care of the children, including the neurologically impaired child, since both parents work. This would automatically mean a switch in the symbol system (from the English spoken at IRM).

The theme of the bilingual home was also broached in the initial interview with parent T. T is exposed to two languages -- English from his father and Spanish from his paternal grandmother, "who understands English, but not too well," according to Mr. T. Mr. T realized that his son is exposed to two languages. The P.D. sees no problem in the acquisition of two languages on the part of a normal youngster: "The younger, the easier"; however, "T has a problem with language, and coping with two symbol systems is difficult." She advised Mr. T to speak English, precisely because his son's main area of difficulty was language skills.

Later the question of bilingualism came up again. Mr. T reported that T talked English to his grandmother but that she replied in Spanish. He said:

"I think it's confusing. I talk to him in English in one way, and she talks to him in Spanish in another way."

The P.D. commiserated with Mr. T:

"Yes, it's hard enough for T to speak, but she's (the grandmother) the one caring for him during the day.

Rare themes which were encountered in only one or two families --

a. Institutionalization of a low functioning child -- The ambivalent attitude of Mrs. N, the upper socioeconomic status mother of a very severely impaired child, was expressed when discharge was discussed midway through the program. "Do I want her (back), don't I want her at all?" Further along, Mrs. N spoke again of her ambivalence and also of her husband's attitude:

"We are people who have never turned away from responsibility. I wanted to send her away a long time ago, but I don't know whether I could. No, I didn't want N to come home... but my husband has placed tremendous burdens on me. He accepts this child as part of his life. She's part of us and can't be forgotten. I don't know at this point... she will have to leave us. We both know this."

Mrs. N expressed a detached attitude toward the child: "I protect myself against super-involvement..." Resisting the pressure of her medical friend, Mrs. N took an opposite attitude, rejecting institutionalization for the moment:

"Dr. O. returned and saw no changes.... Dr. O wants us to put N in a residential situation... it's not the current thing with us; it may be for the future. I told her: 'She's in nobody's way. She's a delight to us. She brings joy as well as heartbreak...' The fact N came to IRM allowed us freedom to go abroad.... This program reincarnated a dying family... we are ready to look at things through rose-colored glasses... accept what is having N

taken care of. This institution, this program, has helped me cope with the problem by letting me get out of it for awhile. I don't know what I'll be like when I have to go back to..."

In an undated post-discharge interview, approximately one year later, Mrs. N finally had made a decision:

"I want her to die in an institution. I couldn't cope with her at home."

The P.D. supported Mrs. N:

"I can't tell you you're wrong. I don't know what the solution is without a fantastic amount of money... what it is doing to the rest of the family who have a life to lead. It's pulling you apart. The kids are not coming home with their friends (reported in a previous interview).

b. Parents' comments about disorder at home -- Parents discuss disorder in the household due to the child's exploratory activities. Mrs. II complained that the child at home pulled everything out of her drawers because he had been taught by his teachers to take things out of a box.

P.D.:

"The only way a young child learns what words mean, i.e., to open, to close, is by doing it. They go through the whole process. They try opening. They try closing."

In a later interview Mrs. II reverted back to the same topic. She interpreted negatively her son's exploratory activities and claimed that she "never had these troubles with my daughters." Three days later Mrs. II reported that the child had learned to push the drawers back again when she instructed him to do so.

Another specific interpretation was given to Mrs. KK, who reported that her son went to her closet and played with her shoes.

P.D.:

"There's something about confining spaces that children find very safe. They're really awed by large spaces. They feel in control in corners, boxes, and shelves because they can feel the boundaries."

c. Significance of specific skills, e.g., babbling, self-feeding, outdoor play, to the development of the child -- An example of specific guidance to an individual parent was found in the following discussion of the importance of babbling for later language development.

P.D.:

"Babbling tells us that he has a mechanism for speech. It also tells you he doesn't have a hearing problem. The youngster is not speaking yet because his maturation is not there yet..."

but he has the equipment to do it. Babbling is a form of speech. It comes before words. And before words comes a kind of jargon. Then unclear words."

3. Do parents express the need for emotional support within the context of these sessions?

We have culled from the transcriptions of parent tapes episodes which indicated that the families of multi-handicapped children expressed the need for emotional support, guidance, and opportunity for catharsis.

Feelings of inadequacy and jealousy of the mother of J that the program is doing more for her child than she could do by herself were expressed in the following interchange:

Mrs. J:

"She was very happy when she came in here. I thought to myself, maybe they have more to offer than I have."

P.D.:

"No, it's not that, you know."

Mrs. J:

"But she was very happy when she came in."

P.D.:

"She's gotten comfortable here. How can any parent spend that much time with a child? When you are here (participation day), she does even less. This means that (other days) she is either with Mrs. B. or Miss W. (teachers) all day long, except when she is sleeping. No home can give that much intensive care. No child needs this constantly. You have 10 other children and household chores to do."

Mrs. J:

"I find I spend more time with her (here) than I do at home."

One mother, Mrs. N, began to imagine that she would like to be an observer rather than a participant in her own family.

"Everybody is taking a different role. If I could observe detachedly as if I were writing a thesis, the whole situation would be very interesting to watch."

P.D.:

"You're not an observer; you're a participant."

The only single parent family where the parent was a male illustrated another situation requiring a great deal of support:

P.D.:

"Do you feel insecure about taking him home after a few months (at IRM), giving him the kind of stimulation he needs? Are you worried about that at all?"

Mr. T:

"I can't actually provide..."

P.D.:

"You've got something else that we don't have. You're his father. A child like T, once he's on the way, has got to learn because he wants to learn. He really does. He's very curious. He's going to motivate himself a lot. And you've learned a lot, Mr. T. I think your mother is going to let him be a little less of a baby and give him a chance to be more independent."

In the course of the sixth interview with Mr. T, when gains in the area of interaction with materials were reported, he sadly remarked to the P.D.:

"You see it, but I don't."

P.D.:

"You should spend more time with Mrs. B and watch a few activities she's doing with him, like using the form box."

Mr. T:

"... as you point these gains out to me, I start realizing that I'm not trained to see those gains... but when you point them out to me, I recall."

In the seventh interview, when it was pointed out that the lessening separation anxiety of the child had built up T's stamina and diminished his fatigue, Mr. T responded:

"Those things you see, I can't, and unless you point them out to me, I can't...."

In the final interview Mr. T was asked:

"Do you feel you are more aware of what to give him as toys?"

Mr. T:

"I'll buy him something that's instructional."

P.D.:

"You know he can learn from sand and water, too -- all kinds of objects. You can take a lot of cues from this little boy about what interests him. I don't think he's going to regress. Twice a week we will have him here (out-patient program referral). We'll watch with you and if we think there are other kinds of activities, we'll tell you."

Subjective feelings of inadequacy remained. It was the unanimous opinion of the P.D. and her staff, however, that Mr. T was a sensitive and motivated observer, participant, and learner with respect to the program. (See Appendix III for case study of parent T.)

Occasionally parents had to be reinforced in their needs to continue their family life without making drastic changes.

P.D.:

"He has to be part of a larger world and not be held in a vacuum."

Mrs. LL:

"I can't stop living."

P.D.:

"He's part of a family, and while his needs are more than those of another child, he has to be part of it. You can't short-change the others or affection for the child turns into resentment."

4. How realistic are the parents of children in the Infant Program? Can this be assessed from the parent sessions alone, or is greater knowledge of individual parents needed?

A realism scale was developed in an attempt to understand the available data. The points along this scale were: (1) grossly distorted, (2) denial or withdrawal from reality, (3) some reality orientation, (4) complete reality orientation, and (5) complete reality orientation plus concern about the future.

All incidents related to questions of "reality" were extracted from the tapes and annotated. These quotations were independently scaled from 1-5 by the principal investigator, Dr. Jacobson, who listened to the tapes. The P.D. and master teacher, who both had extensive contact with parents and children, jointly rated the parents without referring to the quotations. The research coordinator, David Gitler (who had minimal knowledge of the parents) also read the quoted segments and rated them. The three judgments along this scale were then averaged.

Eighty percent (N = 17) of the parents were found to have an averaged rating of 4, indicating a reality orientation. Fifteen percent (N = 3) were found to be somewhat distorted in their view of their children (average of 3 on the scale). The statements of only one parent were scaled at 2, indicating a denial of the reality of her child's status.

Discussion

Our findings fit into the model developed for this study (see page 1); namely, to think through a theoretical construct that would do justice to the interactive, reciprocal nature of the relationship between the Infant Program and the families of multi-handicapped children. What have been the roles played by all parties to this interactive process?

The roles played by the P.D. and parents in the interview process varied. The P.D. was translator (i.e., compiler of observations of other staff members, chiefly teachers and therapists) and observer in her own right, as a questioner of parents on their observations during the weekend which their children usually spent at home, as an interpreter of both her own and the parents' observations, as an explanatory agent with respect to the program, and as a source of emotional support. In general, however, she functioned as a funnel of information, as an interpreter or translator of the therapeutic team's observations and prescriptions.

Specifically the P.D. explained the nature of evaluation, the kind of program specifically constructed for the child, the meaning of activities encouraged for the child in terms of his developmental status (age and disability relevance), the multiple relationships between areas of child development -- emotional, social, cognitive, communicative, and motoric -- the proficiencies and deficiencies and changes over time of the child, the uses of toys for cognitive development, specific child behaviors (separation anxieties, temporary regression, etc.), and, in the last few interviews, she planned for discharge and referrals to other agencies in terms of the developmental status of the child and the parents' own needs and plans (e.g., relocation to a new neighborhood).

The parent, on the other hand, also an observer of his or her child, was most often a recipient of the P.D.'s interpretations and specific guidance. The parents brought up concerns and questions of theirs, fed back information to the P.D., and provided praise -- emotional support on their part -- to the educational staff.

In the lay-expert interaction which took place, language differences between the P.D. and parent often gave way to the assimilation by parents of a "scientific-educational" terminology; that is, the P.D. couched her remarks, at least when the educational level of parents permitted, into professional terminology. Her comments were often simultaneously complemented by gestural language; e.g., "He is plateauing," etc. Thus, some parents in later interviews spoke of the child as having "reached a peak" or "staying more with materials."

The emotional support in interviews with parents was probably one of the main reasons why parents were so satisfied with the program and their relationship to the educational staff, the other being the consequences for their children's development, of the educational and therapeutic program itself, and the guidance concerning more specific problems given by the P.D.

An important lesson which the P.D. and the educational-therapeutic team learned from parents was that each and every one of them was as individuated in his or her concerns, anxieties, expectations, participation level, observational ability, capacity to learn, to accept interpretations and

specific guidance, ability to act upon them and reality orientation, as their children were individuated in their syndromes of impairment and their levels of development and functioning.

The conclusion inevitably follows that counseling of these parents must be finely attuned to their individuated needs and characteristics (as specified above), which means that a structured instrument for asking or answering questions in the process of counseling is counter-indicated, although, in a loosely structured form, it is undoubtedly programmed in the P.D.'s mind.

Thus, it is possible to say that no interview sequence or the process of counseling can be predicted for any parent. The unfolding of interview sequences is specific to each parent or couple and thus, to some extent, is idiosyncratic.

At the same time, the evidence, as it is reported in various sections of this report, indicates that certain themes are constant; sequences of interviews are consistent in their development (i.e., certain topics occur in initial interviews, others in final interviews); emotionally supportive episodes occur in some interviews with most parents (15 of 20); the same basic program assumptions were repeated time and again; a recapitulation of child gains and parent learnings characterizes the final or next to final interview for all parents; and certain themes are subject to interpretation or specific guidance in most interview sequences.

Conclusions

That our findings about parents' attitudes and behavior toward their children, which can be remedied by appropriate guidance, are not unique is borne out by parallel findings and recommendations of a study carried out by Shere (1971). She wrote: "Mothers of children with severe physical handicaps were mainly concerned about the physical handicap.... The mothers wished primarily for their children to progress in the area of physical development, with 'walking' given as the most important activity-wish" (pp. 54-55).

Neither Shere's study nor ours had at its disposal data to draw conclusions about the effectiveness (behaviorally) of the "guidance program" or "psycho-educational counseling," provided to the mothers of multi-handicapped children in these respective service programs. We stress the constraints in that our data are made up solely of verbal behavior, as manifested in interviews between the P.D. and parents. On the other hand, we know that there was almost universal satisfaction on the part of parents with the counseling provided in addition to the satisfaction with the program for their children. This enhances the probability that parents learned how to manage and stimulate their children more effectively as a result of their involvement and participation in the Infant Program at IRM.

Our examination of taped interviews with the parents of 20 multi-handicapped children showed that the overwhelming majority of parents are not fully cognizant of the mental deficiencies of their children -- putting stress on motor handicaps primarily, and that the quasi-totality of parents are unaware of the implications of play (interaction with materials) for the cognitive development of their children. Therefore, prior to their participation in the program, parents did not know how to stimulate their children and select development-appropriate materials.

Cerebral palsied children, slightly older than the infants in our program, inhabited "an impoverished object-environment" and were deprived of opportunities for the needed experiences of object-contact and play (Shere, 1971). Thus, according to Shere, family dynamics played an important role in inhibiting the cognitive development of these handicapped children. A guidance program, educational in character, was instituted to teach mothers to provide the proper object-rich environment needed by these children.

It may be interesting to point out that parents turn to the staff of the program for guidance when they encounter periods of special stress and seem almost incapable of coping with their handicapped children. At such times parents were most suggestible and malleable and more open to change of behavior patterns. It may be that the maximal impact of counseling has occurred at such periods, when there was a great tendency to depend on the educational-therapeutic team for help for themselves and their children.

Thus, since we possess no objective indices of the home behavior of parents, the translation of verbalizations of knowledge acquired by parents in the program into behavior is open to question. The interview data themselves and the subjective ratings of satisfaction (see Satisfaction Questionnaire, Appendix II) are a form of evidence that the counseling

of the P.D. sensitized parents to the variety of dimensions of their children's functioning, besides the motor aspect, and made them aware of appropriate play materials to provide their children. This is, at any rate, what most parents said, both in the latter part of the interview sequences and in the Satisfaction Questionnaire. Since we have no behavioral data, we can do no other than to accept the face validity of parents' reports.

References

- Bentovim, A. Emotional disturbances of handicapped pre-school children and their families: Attitudes to the child. Brit. Med. J., 1972, 3, 579-581.
- Birenbaum, A. The mentally retarded child in the home and the family cycle. J. Health Soc. Behav., 1971, 12.
- Boles, G. Personality factors in mothers of cerebral palsied children. Genet. Psych. Monograph, 1959, 59, 159-218.
- Cook, J.J. Family limitation subsequent to the birth of a cerebral palsied child. Cerebral Palsy Review, 1963 (May-June).
- Evert, J.C. & Green, M.W. Conditions associated with the mother's estimate of the ability of her retarded child. Amer. J. Ment. Def., 1957, 62, 521-533.
- Fox, A.M. They get this training, but they don't really know how you feel: Transcripts of interviews with parents of handicapped children. The Wolfson Centre, Institute of Child Health, London, 1974.
- Gans, Herbert T. The Urban Villagers. New York: N.Y. Free Press, 1962.
- Gumz, E.J. & Gubrium, J.F. Comparative parental perceptions of a mentally retarded child. Amer. J. Ment. Def., 1972, 77(2), 175-180.
- Hall, W.T. Physical handicap and family stress. Cerebral Palsy Review, 1963 (July-August), 9-11.
- Kleinberg, W. & O'Connor, P.A. Appraising the effectiveness of a simple educational approach to problems of retardation and behavior in childhood. Clinical Pediatrics, 1972, 545-548.
- Koch, R., Graliker, B.V., Sands, R. & Parmelee, A.H.Sr. Attitude study of parents with mentally retarded children. 1. Evaluation of parental satisfaction with the medical care of a retarded child. Pediatrics, 1959, 23, 582-584.
- Kogan, K.L. & Tyler, N. Mother-child interaction in young physically handicapped children. Amer. J. Ment. Def., 1973, 77(5).
- Lane, M.B. Education for Parenting. NAEYC, Washington, D.C., 1975.
- Marshall, N.R. & Goldstein, S.G. Effects of three consultation procedures on maternal understanding of diagnostic information. Amer. J. Ment. Def., 1970, 479-482.
- Matheny, A.P.Jr. & Vernick, J. Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived? J. Pediatrics, 1969 (June), 953-958.

- Polansky, N.A., Boone, D.R., DeSaiz, C. & Sharlin, S.A. Pseudostoeicism in mothers of the retarded. Social Casework, 1971 (December).
- Poznanski, E.O. Emotional issues in raising handicapped children. Rehab. Literat., 1973, 34, 324-326.
- Shere, E.S. Modes of child-rearing in cerebral palsy: Effects upon the child's psychological development. The Israel Annals of Psychiatry and Related Disciplines, 1971, 9, 52-59.
- Sheridan, M. The Handicapped Child and His Home. London: National Children's Home, 1965.
- Tew, B., Lawrence, K.M. & Samuel, P. Parental estimates of their physically handicapped child. Dev. Med. Child Neurol., 1974, 16, 494-500.
- Wolfensberger, W. Counseling the parents of the retarded. In A.A. Baumeister Mental Retardation: Appraisal, Education and Rehabilitation. Chicago: Aldine Pub. Co., 1967.
- Wolfensberger, W. & Kurtz, R.A. Measurement of parents' perceptions of their children's development. Genet. Psych. Monogr., 1971, 83, 3-92.
- Zuckerberg, H.D. & Snow, G.R. What do parents expect from physicians? Pediatric Clinics of North America, 1968, 15, 861-870.
- Zuk, G.H., Miller, R.L., Bartram, J.B. & Kling, F. Maternal acceptance of retarded children: A questionnaire study of attitudes and religious background. Child Dev., 1961, 32, 525-540.

Table 1a
Expanded Medical Diagnosis (N = 20)

<u>Child</u>	<u>Medical Diagnosis</u>	<u>Additional Comments</u>
A	Cerebral Palsy (CP)	Congenital, mild right hemiparesis
B	CP	Congenital, post-rubella, spastic paresis
C	CP	Congenital, brain damage, mild spasticity in all four extremities, language disorder
F	CP	Congenital (associated with prematurity), spastic diplegia
H	CP	Congenital, hypotonia, general retardation
J	Brain Damage	Congenital, hypotonia, delayed development
K	CP	Congenital, associated with prematurity (one of twins), left hemiparesis
N	CP	Acquired, hydrocephalus, brain cyst, normal to 3 months
O	CP	Acquired, post-meningitis (at 4 months), spastic left hemiparesis
P	Hydrocephalus	Congenital, shunted
T	CP	Congenital, mild spastic diplegia
U	Delayed Development	Congenital psychomotor retardation
V	CP	Congenital, spastic diplegia, microcephaly, delayed development
W	Brain Damage	Congenital, delayed development
X	CP	Congenital, spastic diplegia
DD	CP	Congenital (associated with prematurity), left hemiparesis
II	CP	Congenital, spastic, quadriplegia
JJ	CP	Perinatal, spastic quadriplegia, visually impaired
KK	CP	Related to neonatal seizures, spastic diplegia, possible hearing impairment
LL	Delayed Development	Congenital, congenital heart defect, visual impairment

Table 1b
Demographic Data on 20 Families

<u>Child*</u>	<u>Sex</u>	<u>CA</u>	<u>MA</u>	<u>IQ</u>	<u>Ethnicity</u>	<u>Socioeconomic Status**</u>	<u>Language in Home</u>
A	M	30	25	83	White American	Low	Italian, English
B	F	33	5	15	Hispanic	Public Assist.	Spanish
C	M	36	24	67+	White American	Middle	English
F	M	35	29	83+	White American	Middle	English
H	M	26	6	17	Black American	Middle	English
J	F	23	14	61+	White American	Low	English
K	M	35	28	80+	Black American	Public Assist.	Spanish, English
N	F	26	5	19	White American	High	English
O	F	30	21	69+	Chinese	Middle	Chinese
P	M	19	11	58+	White American	Middle	English
T	M	24	18	75+	Hispanic	Public Assist.	Spanish
U	F	39	9	23	White American	High	English
V	F	25	11	44	Hispanic	Middle	Spanish
W	F	35	14	40	White American	High	English
X	M	30	13	43	Black American	Public Assist.	English
DD	M	26	9	35	Hispanic	Low	Spanish, English
II	M	31	10	30	Black American	Low	English
JJ	M	22	3	14	White American	Middle	English
KK	M	36	6	17	White American	Middle	English
LL	M	31	6	19	Black American	Middle	English

* Letters are assigned to each child with reference to sequence of entry into the program.

** Langner & Michael, 1963

Table 1c

Medical Diagnosis and Joint Clinical Judgments as to
Degree of Disability and Delay Upon Admission (N = 20)

<u>Child</u>	<u>Medical Diagnosis*</u>	<u>Motor Dev.</u>	<u>Lang. Dev.</u>	<u>Intell. Dev.</u>	<u>Social Dev.</u>	<u>Affect. Dev.</u>	<u>Sum Delay Score</u>
A	CP**	3	3	4	3	3	16
B	CP**	1	1	1	2	2	7
C	CP**	2	2	3	4	3	14
F	CP**	3	4	3	4	3	17
H	CP**	1	1	1	1	1	5
J	Brain Damage	3	3	3	2	2	13
K	CP**	3	2	3	3	3	14
N	CP***	2	1	1	2	1	7
O	CP***	2	2	3	4	3	14
P	Hydrocephalus	3	3	2	4	3	15
T	CP**	2	3	4	4	4	17
U	Delayed Devel.	1	1	1	1	1	5
V	CP**	2	1	2	4	3	12
W	Brain Damage	2	2	2	2	2	10
X	CP**	2	1	2	4	4	13
DD	CP**	2	1	1	2	2	8
II	CP**	2	1	2	3	2	10
JJ	CP***	1	1	2	2	2	8
KK	CP***	2	2	1	1	1	7
LL	Delayed Devel.	2	1	1	1	1	6

* See Table 1a, Appendix I, for expanded medical diagnosis.

** Congenital cerebral palsy

*** Acquired cerebral palsy

Key

1 = Severe delay

2 = Moderate delay

3 = Mild delay

4 = Normal development

Table 2

Parent Tapes Transcribed

<u>Year</u>	<u>Child</u>	<u>Number of Tapes Per Family</u>
1971	A	10
	B	3
	C	5
	F	9
	H	15
1972	J	12
	K	11
	N	12
	O	4
	P	12
1973	T	10
	U	15
	V	6
	W	8
	X	8
1974	DD	9
	II	8
	JJ	14
	KK	13
	LL	9
Total:		191

Item 1

Family P
November 13, 1972

M	En	So	Co	AF	MO	MO	Annotations	Context
			Sp+ Sp+	Sp+			He is good about P.T. Better with strangers	
		Sp+ El+		Sp+			Awareness of playing with other children	
							Good behavior, no crying once during wedding	
							After dinner played quietly with spoons on floor. S. had also brought toys. His father was so proud of him; if nothing else it told us we could take him anywhere.	
							Someone came to dinner and saw a difference in him. He's alert and he gets angry.	
					El+		Mrs. P.: "How's his development?"	
							Mrs. P.: Feels so much better not to hear him crying; kisses her good-bye; one child is friendly to him. Project Director: may form new attachments here.	
							Husband is baseball fan and wants him to be athletic. He is so pleased every time he hears something new. He plays with him.	
								Project Director counsels about family life; don't make your son center of your life. Parents have rights too, and he must understand that schedule for children is not sacred.

KEY

Sp : Spontaneous
El : Elicited
+ : Positive
- : Negative
Sp or El : Parent
Sp or El : Project Director

Table 3a
Coding Comparisons for Taped Sessions with Parents: All Dimensions,
All Time Periods (Parents of Children O and X)

	Child O			Child X		
	# of Codings			# of Codings		
	CJ*	OE**	CJ	CJ	OE	OE
Statements during Sessions:						
Parent	18	14	47	40	38	58
Project Director	20	13	53	25	27	42
Total	38	27		65	65	

Spontaneous Statements:

Parent	5	6	25	23	7	53	38
Project Director	15	8	75	20	18	47	62
Total	20	14		43	25		

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Responses:

Parent	13	8	72	17	51	77	78
Project Director	5	5	28	5	9	23	22
Total	18	13		22	40		

Positive Statements:

Parent	14	12	41	29	30	54	54
Project Director	20	13	59	25	25	46	46
Total	34	25		54	55		

* Principal Investigator
Listened, annotated, and coded.
** Statistical Analyst
Listened and coded.

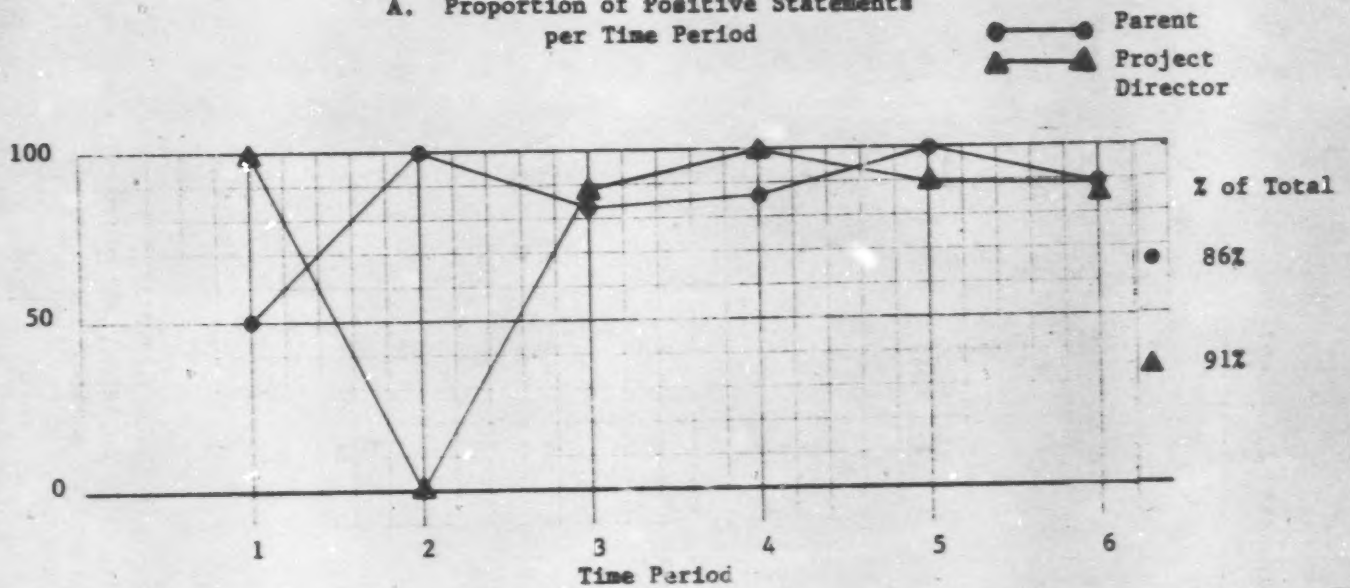
Table 3b
Coding Comparisons for Taped Sessions with Parents: By Dimension,
All Time Periods (Parents of Children 0 and X)

	Child 0						Child X					
	# of Codings		% of Total Codings		% Per Dimension		# of Codings		% of Total Codings		% Per Dimension	
	CJ*	OE**	CJ	OE	CJ	OE	CJ	OE	CJ	OE	CJ	OE
<u>Interaction with Materials (M)</u>												
Parent	1	1	6	7			10	9	24	24		
Project Director	4	1	20	8			7	7	28	26		
Total M	5	2			13	7	17	16			26	25
<u>Awareness of Environment (En)</u>												
Parent	0	0	0	0			2	1	5	3		
Project Director	0	0	0	0			1	1	4	4		
Total En	0	0			0	0	3	2			5	3
<u>Social Responsiveness (So)</u>												
Parent	0	0	0	0			1	1	2	3		
Project Director	1	0	5	0			1	2	0	7		
Total So	1	0			3	0	2	3			2	5
<u>Expressive Communication (Co)</u>												
Parent	4	2	22	14			9	8	23	21		
Project Director	4	2	20	15			8	6	21	22		
Total Co	8	4			21	15	17	14			26	22
<u>Affect (Af)</u>												
Parent	3	3	17	21			9	6	23	16		
Project Director	4	4	20	31			3	2	12	7		
Total Af	7	7			18	26	12	8			18	12
<u>Gross Motor (MO)</u>												
Parent	10	8	55	52			9	13	23	34		
Project Director	7	6	35	46			6	9	24	34		
Total MO	17	14			45	52	15	22			23	33

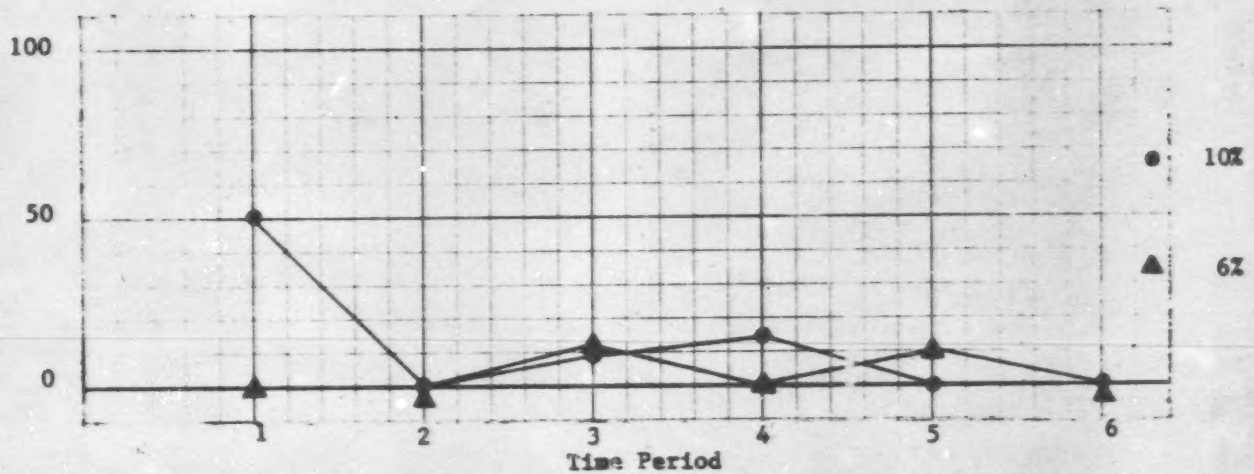
* Principal Investigator
Listened, annotated, and coded.
** Statistical Analyst
Listened and coded.

Figure 1a
Parent P

A. Proportion of Positive Statements
per Time Period



B. Proportion of Negative Statements



C. Proportion of Ambivalent Statements

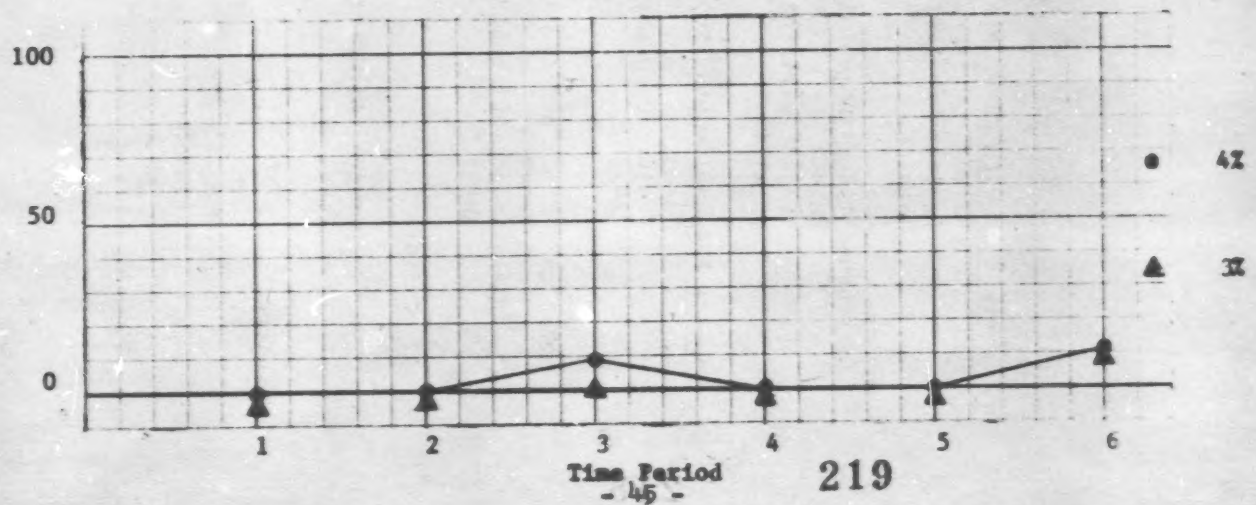
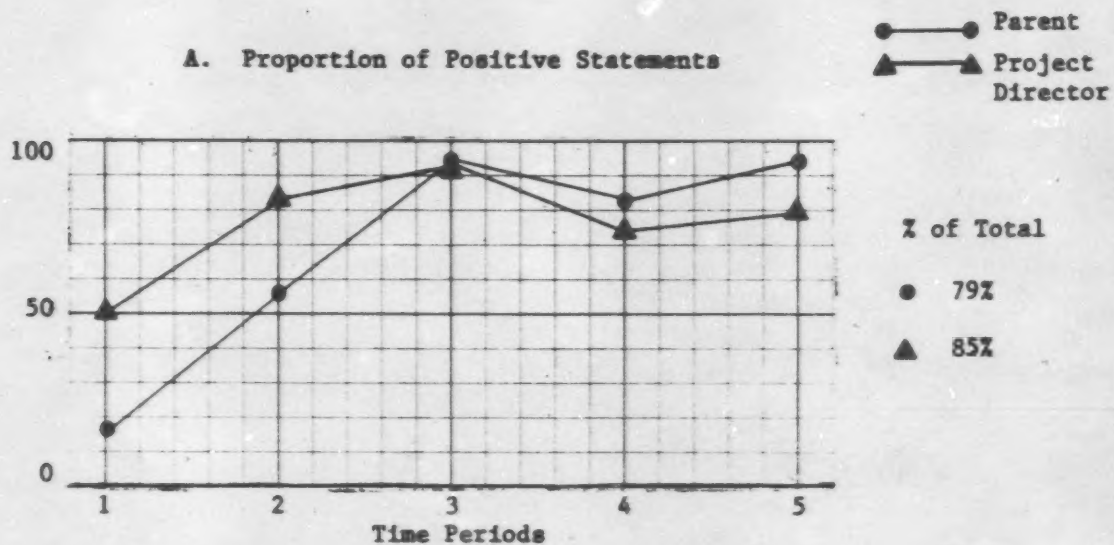
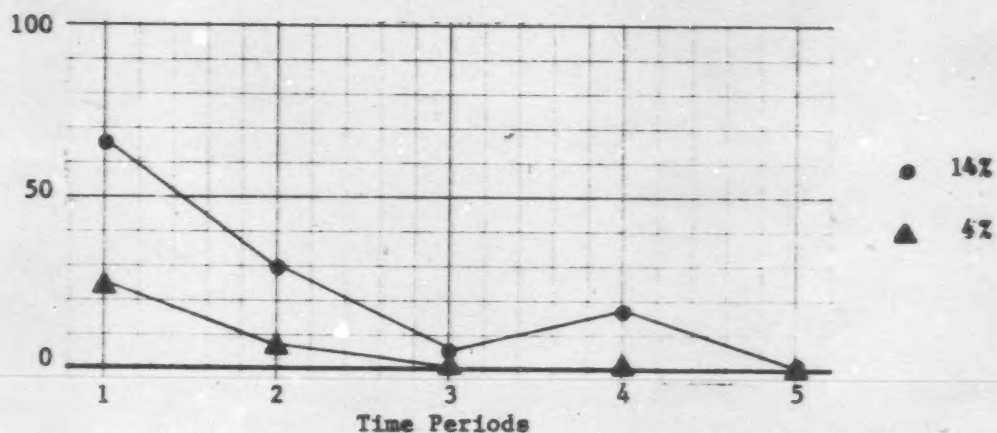


Figure 1b
Parents J

A. Proportion of Positive Statements



B. Proportion of Negative Statements



C. Proportion of Ambivalent Statements

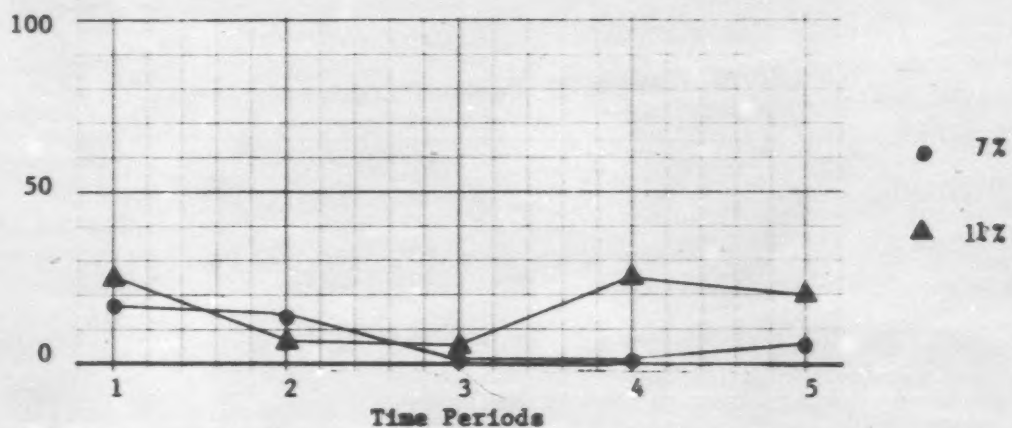


Table 4

Analysis of Parent Tapes*
Percent Per Dimension Across Time Periods

P = Parent
PD = Project Director

Family P													
Dimension	1		2		<u>% Per Time Period</u>		4		5		6		<u>% All Time Periods</u>
	P	PD	P	PD	P	PD	P	PD	P	PD	P	PD	P PD
M	60	0	0	0	0	11	0	0	21	10	45	11	20 12
En	0	100	33	0	0	0	0	50	0	20	0	22	2 19
So	0	0	0	0	0	22	29	0	21	20	11	11	12 16
Co	20	0	33	0	45	56	29	50	21	30	22	34	30 38
Af	0	0	0	0	36	0	13	0	30	0	11	11	20 3
MO	20	0	33	0	19	11	29	0	7	20	11	11	16 12
mo	0	0	0	0	0	0	0	0	0	0	0	0	0 0

Family J													
Dimension	1		2		<u>% Per Time Period</u>		4		5				<u>% All Time Periods</u>
	P	PD	P	PD	P	PD	P	PD	P	PD	P	PD	P PD
M	17	0	13	8	21	16	29	0	28	17			21 11
En	0	0	13	23	4	0	0	0	11	17			7 9
So	0	25	0	0	4	21	13	25	6	0			4 13
	33	25	20	31	21	21	29	25	33	17			27 24
	17	25	7	15	25	21	0	0	22	17			17 17
		25	47	15	25	21	29	50	0	32			24 24
		0	0	8	0	0	0	0	0	0			0 2

*Principal Investigator

Table 5a

Quantitative Data on 20 Parents:
Means and Standard Deviations of Responses by Type and Quality

	<u>Parent</u>		<u>Project Director</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
Total Number of Responses:				
$\bar{x}$	7.90	12.30	5.70	7.05
SD	5.96	7.78	4.21	3.61
Percent of Total Responses:				
$\bar{x}$	54.25	60.55	45.75	39.45
SD	21.83	19.76	21.83	19.76
Percent of Spontaneous Responses:				
$\bar{x}$	42.45	59.20	65.65	66.55
SD	27.87	20.64	24.95	24.45
Percent of Responsive Responses:				
$\bar{x}$	52.55	40.80	34.35	33.45
SD	28.81	20.64	24.95	24.45
Percent of Positive Responses:				
$\bar{x}$	51.80	74.60	77.20	90.75
SD	23.01	22.50	29.07	12.55
Percent of Negative Responses:				
$\bar{x}$	31.35	19.10	13.00	3.95
SD	21.86	23.41	19.13	9.10
Percent of Ambivalent Responses:				
$\bar{x}$	11.80	6.30	9.80	5.30
SD	12.03	7.62	23.87	8.63

Table 5b

Quantitative Data on 20 Parents:Means and Standard Deviations of Responses
in the Seven Psychoeducational Dimensions

	<u>Parent</u>		<u>Project Director</u>	
	<u>% of Responses</u>		<u>% of Responses</u>	
	<u>Pre</u>	<u>Post</u>	<u>Pre</u>	<u>Post</u>
Interaction with Materials:				
$\bar{x}$	13.90	28.30	23.05	30.60
SD	15.84	15.05	21.79	23.24
Awareness of the Environment:				
$\bar{x}$	3.95	4.15	3.10	5.35
SD	8.40	7.73	11.36	12.60
Social Responsiveness:				
$\bar{x}$	6.80	8.90	11.65	8.00
SD	10.29	9.13	26.40	12.94
Expressive Communication:				
$\bar{x}$	20.70	28.25	16.50	26.15
SD	14.39	19.77	19.61	15.50
Expression of Affect:				
$\bar{x}$	20.95	11.55	20.70	9.90
SD	18.36	11.76	20.03	11.25
Gross Motor Ability:				
$\bar{x}$	28.60	18.75	24.90	19.05
SD	20.92	14.75	26.99	15.19
Fine Motor Ability:				
$\bar{x}$	0	0	0	0.40
SD	0	0	0	1.79

Item 1

Satisfaction Scale: Illustrations for ScoresChanges in ChildScores

- 1 No improvement or ambivalence of parents; no changes seen in child; parents did not get what they wanted. Ex. "I expected a miracle... he's not doing what I expected" (JJ).
- 2 Small gains. Ex. "I am pleased with J's progress" (J). "Neither my husband nor I had expected these gains" (N).
- 3 Considerable gains in some areas. Ex. "I had hoped he'd be walking but he's making real progress... his muscles are real strong now" (P).
- 4 Considerable gains in all areas. Ex. "She's done so spectacularly" (U).
- 5 Complete change in child. No examples in our sample.

Changes in Attitudes related to ProgramScores

- 1 Dissatisfaction. Ex. "I have a feeling that doctors tend to withhold.... My point here is I have no intention of suing anybody..." (W).
- 2 Qualified satisfaction; change would have occurred regardless of intervention. Ex. "I'm real pleased... I'm a very hard person to please.... But he didn't get as much attention as I would give him" (II).
- 3 Simple satisfaction. Ex. "We saw how good he was doing here. We hate to take him away from here" (KK).
- 4 Elaborated satisfaction. Ex. "I'd like to say I've never met so many people that really care about the child and what is happening to him and really want to do something.... The teachers were completely different. You can't even compare them... (to run-of-the-mill teachers)" (KK).



Item 2

Satisfaction Questionnaire

NEW YORK UNIVERSITY MEDICAL CENTER

Institute of Rehabilitation Medicine
400 EAST 34TH STREET, NEW YORK, N.Y. 10016
AREA 212 679-3200
CABLE ADDRESS: NYU MEDIC

The George G. Deaver Children's Division

May 8, 1975

As part of our responsibility to report to the U.S. Office of Education, which, as you know, provided support for the development of our Infant School, we have to submit a final report to Washington concerning our work both with children and families in our program.

I would so much prefer speaking with you personally about your reactions, but time doesn't allow me this luxury. Therefore, I am sending a short series of questions for you to answer that will help us to evaluate how effectively, or inadequately, we were able to satisfy the parents with whom we have been involved.

I do encourage you to be frank in your statements rather than to answer the questions in a complimentary fashion. Your honest responses can help us to learn what we do well and what we need to improve upon.

I would appreciate your filling out this questionnaire immediately and returning it in the enclosed self-addressed stamped envelope within the next week. We are pressured for time.

I would also hope that you use the space allowed for comments to give me news of your child's progress that we have not already shared. It has been a long time since I spoke to you.

Sincerely,

Ronnie Gordon
Associate Professor of Clinical
Rehabilitation Medicine
Director of Pre-School Developmental
Programs

RG:ms
Enclosure



NEW YORK UNIVERSITY MEDICAL CENTER

Institute of Rehabilitation Medicine
400 EAST 34TH STREET, NEW YORK, N.Y. 10016
AREA 212 679-3200
CABLE ADDRESS: NYU MEDIC

The George G. Deaver Children's Division

QUESTIONNAIRE FOR PARENTS OF INFANT SCHOOL PATIENTS

1. Did your child make gains in the Infant Program to the extent you hoped for? To a lesser extent? To a greater extent?

Extent hoped for ()
Lesser extent ()
Greater extent ()

2. Were you satisfied with Professor Gordon's explanations and instructions during your interview sessions with her?

Completely ()
Partially ()
Hardly ()

3. Has what transpired during these sessions been helpful to you?

Yes ()
No ()

In what way? _____

4. Do you think that your child would have made the same progress had he or she not been an in-patient in the Infant Program at IRM?

I don't think so ()
I think so ()
I am not sure ()

- 2 -

5. Additional comments:

Qualitative Analysis of Post Discharge
Satisfaction Questionnaire for Parents

The brief questionnaire, designed to elicit the attitudes of parents toward the program and their assessment of the progress made by their children in the program was designed and sent out in May, 1975. This questionnaire included four structured questions, which were pre-coded, and two open-ended questions (one related to a structured question, the other asking for additional comments).

Seventeen of 20 questionnaires (85%) were returned to us. All those parents whose address was known to us (or to whom the letters could be forwarded) returned their questionnaires. The three remaining parents could not be located. The return of questionnaires (of parents who could be located) indicated the quasi-universal satisfaction of parents with the program. Seven (over one-third of our sample) sent back the questionnaire with letters thanking the P.D. and her staff for their dedicated work with the children. Two families even sent photographs.

Comments related to the open-ended question (question 3: in what way have sessions with the P.D. been helpful to you?) can be grouped according to the underlying theme -- the information provided by the P.D. and the ensuing understanding of parents:

1. Sensitization to problem areas
2. Knowing what was being done to the child in IRM
3. Knowing what the child's developmental status was at various points of time
4. Learning different approaches to the child; getting specific guidance to help the child
5. Learning about appropriate toys
6. Feeling involved in the program
7. Receiving good post-discharge referrals
8. Parental catharsis

Some typical verbatim comments follow:

"There isn't any word we can find to say thank you to all of these people" (Mrs. K).

"The sessions answered my questions and prepared me to help my child to the fullest extent" (Mrs. LL).

"We developed considerable insight into the nature of W's predicament as a result of discussions" (Mr. W).

"Speaking to the P.D. was a satisfaction second only to watching our daughter's spectacular progress. These sessions helped us gain an understanding as where U was in her development, what could be next for her and what might be expected of her. Moreover, the P.D. displayed such sensitivity and understanding of U that we felt enormous trust and confidence in the program. We, thus, were inspired to fully cooperate with their efforts. This undoubtedly helped to make the program as successful as it was. Finally, we believe that by being so fully informed and so closely in touch, we were able to carry on many of the principles and teaching methods we learned while U was at the Institute as an in-patient. Once U came home, much has changed in the way we treat her, as now we have a better understanding of what her needs are and what is effective in helping her learn and progress" (Mrs. U).

"Catharsis is a difficult thing to go through, but the result has got to be beneficial if the procedure is done long enough and not permitted to get out of hand" (Mrs. N).

The open-ended question (question 5, "additional comments") elicited a variety of comments:

1. Progress of the Child --

"T has progressed motor-wise, he differentiates concepts... likes to be read to... the progress is due to the help provided by IRM.... T will lead a normal, happy life" (Mr. T).

"KK has progressed in every area -- self-feeding, standing, babbling, understanding, crawling, less biting of hands, happy at school" (Mrs. KK).

2. Parent Meetings --

"I was pleased with the parent meetings -- there was a sharing of problems which leads to improvement in what parents do" (Mrs. H).

Quotations from Letters and Comments

Mrs. F:

"I think programs like these should continue and expand because there's so many children in desperate need of them, and if these children are neglected, what is to become of them? The main reason I feel so strongly in favor of these programs is because of the progress my son has made as a result of it.

As a result of his three months' stay, my son could walk, was feeding himself, and was making marked gains and learning skills, all of which is still with him today. The program, needless to say, also helped me tremendously as to how I could help F at home. I also learned the proper materials to buy for him at home to play with, how to give him physical therapy at home, what school to enroll him in, and what areas I should have patience with.

Today, although a year behind, F is attending a "regular" kindergarten class in our neighborhood school... he still has a moderate perceptual problem, and balancing problem which he will be getting treated for at the.... The reason for my entering F at the Center is because I've recently moved to the Island and the long trip into the City was too much.

F has been evaluated at... and they have all his records. From their evaluation, he has come a long way and we are very proud of his achievements and very thankful for all the especially trained people it took at the hospital to get F where he is today. I hope with a little more additional help, F can lead a normal and productive life."

Mrs. K:

"Our son made the greatest improvement. And we urge you all to continue doing the same job, so you can help other parents the same as us."

Mrs. P:

"We have been involved in several different programs since we were at NYU and I feel it's one of the best programs for pre-school children I have ever worked with. The parental involvement is tremendous and most of the children seem to make great strides while they are in the program."

We register two complaints (10% of the parents):

"The time spent working with children should be longer each day" (Mrs. KK).

Mrs. X, in a letter to the P.D., complained about the limitations of physical therapy and speech therapy:

"They should have been 'longer' or 'better.'"

Other complaints centered around the out-patient program, which some parents felt should have been more extensive and intensive (parents LL and JJ). There is also the following complaint:

"There should be emphasis on a home program parents could go by" (Mrs. DD).

Quantitative Analysis of Precoded Questions
in Parent Satisfaction Questionnaire

1. Did your child make gains in the Infant Program to the extent you hoped for? To a lesser extent? To a greater extent?

	<u>Percent</u>	<u>Number</u>
Extent hoped for	24	4
Lesser extent	17	3
Greater extent	59	10

2. Were you satisfied with Professor Gordon's explanations and instructions during your interview sessions with her?

Completely	94	16
Partially	6	1
Hardly	0	0

3. Has what transpired during these sessions been helpful to you?

Yes	100	17
No	0	0

4. Do you think that your child would have made the same progress had he or she not been an in-patient in the Infant Program at IRM?

I don't think so	88	15
I think so	6	1
I am not sure	6	1

Five Case Studies of Families

Space limitations oblige us to limit our family case studies to five and the narration to central themes emerging in each family. Our choice of families is designed to introduce the reader to the extraordinary variety of parental concerns and kinds of family functioning encountered in the total sample of 20.

Thus, (1) Family C can be characterized by marital conflict, centering on each parent's assessment of the capacity and potential of their impaired child; (2) Single-parent family O is made up of the mother and two children, the father having deserted Mrs. O (the family is of immigrant stock, being recent migrants from Hong Kong); (3) Family W, of upper socioeconomic status, is characterized both by extreme intellectualization of the problems posed by his child on the part of the father and the constant reiteration of feelings of inadequacy in parenting by the mother; (4) Family J, in terms of the mother, suffers from tremendous separation anxiety and a virulent anti-institutional bent; it can also be characterized as having an extremely cohesive sibling structure; (5) Single-parent family T is made up of a male parent, whose wife deserted him and their impaired son; this parent was judged successful in assimilating the educational approaches and toy selection processes of the program staff. We stress success in this case, though three-quarters of the other parents also incorporated educational principles of the program (see p. 9), because we are dealing with a male parent of Hispanic origin, whose role as a nurturing and socializing father is a reversal of the normative definition of the male role in Hispanic culture.

Family C

Parents C are white, of middle-class status. Their child was one of the less severely impaired children. The learning of educational approaches by the mother was characterized as uncertain by the Project Director.

Our data on this family consists of five interviews over a period of 6 weeks. In the first interview, the parents express communication as the primary goal for their child, followed by the goal of walking. Already at this stage (date when the child was admitted to IRM) the parents diverge on the hope-fatalism continuum.

Mr. C: "I don't expect it (for him to talk and walk) but I'd like it. I'd try not to build myself up so that I won't be disappointed."

Mrs. C: "I do expect it."

The father believes, due to a previous evaluation at another source, that his son (who was 3 years of age) is functioning physically and mentally

at a 10-month level. The mother disagrees: "In comprehension he is almost normal, he has good mechanical ability and he plays appropriately with toys." The P.D. intervenes to say that he may be functioning higher in some areas than others and that a complete assessment will be done shortly. The father, nonetheless, reiterates his underestimation of the child: A doctor had told him that the child was 50% retarded; thus, at 3 years he would act like an 18-month old:

"I've been concerned that he's slipping. He's not equivalent to an 18-month old now. An 18-month old can walk, talk and feed himself easily."

The father explains his disappointment in his son and the mother comments appropriately:

Mr. C: "His sister runs circles around him (sister is 4 years old)."

Mrs. C: "It's especially hard for my husband. He'll leave the room. He just doesn't want to see the comparison working."

...Mrs. C: "I've had to accept him completely and my husband hasn't fully accepted it."

Mr. C: "It's not a question of acceptance, it's a question of disappointment. I wanted a son and when my daughter was born, I was heavily disappointed. I was heartbroken. Now I wouldn't trade her for the world... Still I feel that I don't have a son, in the respect that I can take him fishing and play ball with him. Would he be useful - I'm thinking of 15-20 years from now - be productive in society, do something? This is impossible to tell, but this is the way I look at things."

In the second interview, observations are exchanged between Mrs. C and the P.D. The latter interprets the anger and temper tantrums of the child, beating and pulling the hair of his mother during the course of his mother's participation day as manifestations of separation problems which are common during the course of the first week of the in-patient stay of the child. The P.D. advises the mother as follows:

"It's critical that when you leave you say: 'Good-bye, I'm leaving, I will be back.' And, some members of the family should visit during the week."

The mother reports that the child was happy to see his father and sister over the weekend. To the P.D.'s query about her husband's feelings on seeing his son, Mrs. C turned the question around to how their son felt about seeing his father.

At the third interview, the mother reported her observations of her son's progress in language, peer group activities, possessiveness and fighting behavior with his sister, which the P.D. interpreted positively - as appropriate behavior for a child of his developmental level. An interchange occurred about disciplining the child - where the mother spanked her son and the P.D. expressed her preference for holding him and talking to him and also reinforced Mrs. C's assessment of her child, as contrasted with the father's evaluation:

"In some areas he's doing a little bit above, in some areas a little bit below. His language is the area of greatest delay. It's certainly not at 10-month level (as Mr. C thinks)."

The P.D. again inquires into Mr. C's feelings about his son - inquiries the mother initially ignored.

Later in the interview, she asks point blank about whether Mrs. C's husband has seen any growth in the child. Mrs. C then relates the ambivalence of the boy's father:

"I don't know, he admits hospitalization was helpful. He was impressed by speaking to him...Our biggest fight is that he calls names at C. It just tears me apart - retarded, stupid and idiot. But mostly retardate... It's a word I cannot stand. I will not use it. But when my husband does it, it's anger...and I don't want him to take his anger out on the child. That's what I'm afraid of...when my husband speaks to him and he ignores him, he calls him the retardate. It's just that he wants to be able to speak to him and for him to do or say something. My problem is I'm concerned about my husband. He has hit C..."

And Mrs. C adds:

"One day he plays with him like it should be between father and son. One day the other side comes out."

The P.D. then offers some specific guidance and makes an interpretation:

"The child is not what your husband wanted, but he's much more than he thinks he is."

Mrs. C: "That's what I'm hoping you can prove to him. That C can be made more than he is."

P.D.: "We can only prove it if he looks at C with fresh open eyes. Maybe your husband should come in and sit down with Dr. G and me and the psychologist and go over what we know about C. Maybe with a boy, it's a harder thing for a father."

During the fourth interview, Mrs. C reports motoric and language changes and more continued interaction with materials, and she offers proof of validation:

"The neighbors have seen changes and I have a friend who comes every Saturday just specifically to see what new things he's doing. She's amazed, especially at his vocabulary."

Discharge plans are announced by the P.D. for the end of July, since there is no educational program in August and since the parents are moving to Connecticut. The P.D. feels the child should make the move with the family. She advises Mrs. C to bring the child back in the fall for the out-patient educational program or secure a place for him in a special school with a

small enough teacher-child ratio to permit considerable stimulation of the child. The mother expresses the desire to learn how to do PT exercises with her son at home.

Mr. C's assessment of the child is that no significant changes have occurred.

Mrs. C: "I said: 'Can't you see it?' And he said, 'You just want to see it.'" To which Mrs. C retorted: "C's attitude has changed drastically... He doesn't want something and he screams and hollers now. My husband has said he's learning to be incorrigible in the hospital and he didn't know how to handle it. We don't want to undo what you do all week...I told my husband I was glad to see it. You've been hollering at him for 3 years, now he's hollering back at you. I think it's a feeling of self-worth, but my husband thinks he's being a wise guy."

Yet one important change noticed by the child's father is that the boy now recognizes him as being "Daddy"... because it's 'Hi, Dad.' Nevertheless, when Mrs. C asks her husband:

"Do you see any changes?" He replies, "No, not that much."
"That's when he said I was making these things up."

The final interview consists of observations of progress by the P.D., the mother, although the latter also points to recent regressions in the area of play ("He's back to doing the same old thing, playing with cars"), which the P.D. interprets as a pacifier, used in response to tensional situations. Problems with eating at home are reinterpreted as an example of self-assertion, typical of most 3 year olds and she advises Mrs. C to be casual and walk out of the room.

Mrs. C expresses her disappointment that changes have not been more marked in the final weeks. The P.D. points out the child's improvement in play, motoric progress and vocabulary increase.

Mrs. C reports that the child's sister was "trying desperately to teach him new words because she has seen me do it. She tried to get him to say her name: Nanine. She got 'Anine'...she was so excited. The child's father's assessment is that his son has changed in 'just a few things'."

Follow-up plans are again discussed - in the form of what nursery school the child should attend in the new neighborhood to which the family is moving. Mrs. C is disappointed that the PT department repulsed her desire for specific exercises, saying that the problem was not in the child's muscles, but in his balance.

"I thought I understood correctly that as important as C's being here was my learning how to handle him." Mrs. C announces that "one of my main purposes once he comes home is to buy a bunch of educational toys." In relation to which the P.D. offers guidance upon selection and advises Mrs. C to get rid of the cars, keeping only one as a potential pacifier - "He will not regress."

Family O

In the initial interview, the P.D. communicates her awareness of the separation anxiety felt by the child and the mother, a theme which comes up in all four interviews. She explains the anxiety in terms of the closeness of mother and child and stresses the fact that, when Mrs. O is not there, her daughter is laughing and having a good time:

"She's settling down. You'll never see her as happy or as settled (as we do) because when a mother comes, the child actually wants to be with the mother. Very often we have the mother watch from the nurses' station to see the child play, or else use tapes, so that you know that when you aren't here, she does settle down."

Mrs. O remarks on a comment of Dr. G which impressed her immensely:

"I spoke to Dr. G. He said O is beautiful."

This is a culturally significant theme, probably universal, although beauty is defined differently in different cultures, but especially important in Far Eastern societies.

The remainder of the interview is devoted to Mrs. O's focus on the physical looks and functioning of the child, to which the P.D. is responsive, although she attempts to communicate to Mrs. O the importance of other areas of functioning.

Mrs. O complains about the child crawling on the floor with the well-functioning right side of the body (the child is a hemiparetic with left upper and lower extremities involved). She wants her to use the other (left) side. The P.D. explains the child has to use what she has and crawling is good for her. However, PT exercises will strengthen the other side of the body, and motivation (getting her active and interested) will encourage the use of both hands. P.D. explains that the left side is damaged and will never be like the right side and she cautions:

"Don't deprive her of the use of her right hand." (to Mrs. O's suggestion of strapping down the right arm - to force use of left one)

Mrs. O: "The main thing for O is to make her exercise her left, right?"

P.D.: "The main focus for O in this Infant Program is all of O, not just her physical development. We want her to work with materials that are right for her to help her mentally, too."

The P.D. has to repeat her explanation that the right side, which is well developed, should not be discouraged from functioning, but that the left side, too, will be concentrated on in PT.

Mrs. O suggests using a machine for making O use her left side. The P.D. explains that motivating the child is the answer:

"It's got to be something that comes from the child."

Furthermore, as she explains, movement comes in the form of a message from the brain:

"It has to come from within her, this is what I'm trying to say... Our job is all of O, not just the one side... the purpose is not just to have O walk better and use her hands better. She has to use her mind better, so stimulation of every part is important."

There is a glimmer of understanding on the part of Mrs. O that a great deal depends on the child herself:

"It depends on herself alone" to which the P.D. responds:

"It depends on her and you, and our teachers and therapists to help her to use what she has."

Mrs. O: "I am less concerned about her hand because she's a girl. Her hand, if one inch shorter, does not make any difference. You don't notice that much. If the leg is an inch shorter, you will walk very awkwardly or need a special shoe, and it doesn't look good for the girl."

The P.D. reminds Mrs. O of the impossibility of making the leg longer, although there will be stretching exercises:

"What I'm trying to say is that we hope you trust us. We do it in a way that we've learned from experience is the right way. And it won't be by forcing her not to use the side (right) that's good. The child wouldn't do anything. She will resist you and she will resist me, the psychologist, and the doctor. While if we get O to get excited about what she's doing, we can stimulate her to want to reach with the hand that's not good. She's always going to work with the hand that's good. Why shouldn't she? It's more effective. It's like saying - if I'm a very strong righty, to use my left hand. It's silly. Why shouldn't I use my right hand? But if I have to do something with two hands...you have to regard the hand that's smaller as an assisting hand... If O is interested in things, she's going to want to use it if her interest is deep enough. It won't be by stopping her, it will be by encouraging her, really."

To which Mrs. O replied that "I trust the hospital. I know it's the biggest hospital on the East side."

The P.D. then suggests to Mrs. O that she make an appointment to see Dr. G about her concerns related to the physical-medical aspect of her child's impaired functioning and the general evaluation by the educational-therapeutic team.

P.D.: "You're putting all of your stress on the physical and I guess I'm trying to say: I think we have to work with all parts of O because it is important that she do well in school. Sometimes we can do more about that than something that is a physical problem. Her personality is important."

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Mrs. O: "She's too young to think about that, right?"

P.D.: "Oh no, it will develop now, Mrs. O. If the child is curious and wants to do things - all of this develops right now. And that's why we like to work with the youngsters early. A child will get a good deal of pleasure from learning now...she'll then be the child who will like to learn in school. It doesn't just 'happen' at 6 or 7 years. It develops. That's very important, because that's what makes you more satisfied."

Mrs. O's emphasis - the physical disability (especially of the left leg) of her daughter is culturally significant. This is emphatically countered by the P.D.'s attempt at making the mother aware of all the dimensions of the child's functioning while minimizing the physical. Mrs. O, a first generation Chinese immigrant, is undoubtedly thinking of the future marriageability of her daughter. In traditional society, bodily integrity is very important for marriage, especially in the case of women.

In the second interview, there is a long discussion on the separation anxiety of Mrs. O's daughter, expressed through crying, and Mrs. O's own separation problems, which arose when she came to see her child at IRM over the weekend, took her home for half a day, and brought her back to the hospital.

Mrs. O has become convinced, that when she's not at IRM, the child "gets adjusted" and that she, too, will shortly become adjusted to the separation. Mrs. O's perceptions are reinforced:

"I think it's important to know that she doesn't act this way when you aren't here. After a while...children can have their parents here and they continue playing and working with the teacher and the therapist while the parent is here..."

Mrs. O relates the behavior of her daughter where the latter's separation anxiety completely precluded activity on her part:

"When I went out and my babysitter keeps her home, she just sits herself in front of the door waiting for me and she waits for me 1½ hours. Just sits there, doesn't move. And she can wait the maximum time of 1½ hours. She didn't say anything. She knows I'm coming back."

Observations are exchanged between Mrs. O and the P.D. about O's use of her left hand, greater endurance in walking, use of more words, diminished problems with feeding and progress in toilet training. As in the previous interview, Mrs. O is advised to watch the child from the nurses' station before the child sees her mother on participation day.

"So you have an idea of what she's doing before she gets anxious because you're here... It would give you a better idea, too, of what people are doing with her."

A supportive episode occurs at this point - focused on separation anxiety,

wherein Mrs. O draws generalizations about the contrast between "American" and "Chinese" cultures, in families' treatment of their children (more dependency in China, greater independence in America). She shows her own ambivalence about which way she should choose for herself. The P.D. then suggests that the "American way" is more suitable, since the family will be living in the United States and not in China.

This interview concludes with Mrs. O's revelation that the child is used to sleeping in the same bed as her mother. American and Chinese cultural themes are again evident, as is Mrs. O's ambivalence about how she should choose, in the following dialogue.

P.D.: "That may be why the first night (at the hospital) she had a hard time. It's good for her to know that she can sleep by herself. It's part of growing up, too, being more mature."

Mrs. O: "Actually, we don't sleep with the children, but when the baby is so small, she gets scared so easily if there's a strange sound. So we believe if we sleep with her, she'll be more secure."

P.D.: "But you said (before) you think the American way is better..."

Mrs. O: "It makes them more independent and it's more hygienic sleeping alone."

In the course of the third interview, the P.D. and Mrs. O exchange observations about the child's walking, use of her hands, and cognitive functioning. Very soon the topic of separation anxiety of both child and mother becomes again the focus of attention. The following dialogue ensues:

Mrs. O: "Last Sunday when I took her back, she didn't cry and she understood."

P.D.: "Big improvement."

Mrs. O: "And I told her that she was going back here to sleep here."

P.D.: "This kind of preparation is so important to children. Not too far in advance. It's easier - to get across to her: 'I'll visit you, then you come home.' You set up a way of thinking about actual time sequence."

Mrs. O: "It's not just a month."

P.D.: "In O's case, she has the extra problem of a different culture. You are even closer to her than many of American parents. Maybe it'll take 5 to 6 weeks. She must understand you're coming back."

Mrs. O: "I don't think she understands."

P.D.: "But you have come back. Language isn't enough. The child

has to see it happen. In 4 weeks she's seen it happening. It has to be back and forth until she understands with her whole being that this is the way it is. Then she can put words together with it. When she's older you can just say the words. But at 2 or 3 (years of age) words aren't enough, until she sees it as part of her life. She's relaxing more (here at IRM). She knows you're coming back."

Physical concern then dominates Mrs. O's conversation - Mrs. O's complaints about changes of temperature in the Infant Room, which could cause her daughter to catch a cold. (The P.D. reassures Mrs. O that temperature is checked, children are checked, and that both of them can make double sure by talking to Mrs. R, the head nurse.)

When the P.D. informs Mrs. O that the educational program will be reduced in August, but that the child will get PT, Mrs. O's response is as unbending as in the first interview:

"It's all right. PT is the most important."

When the P.D. begins to stress the intellectual component, Mrs. O says:

"Most people think that the mind is the most important thing. I still think that a person should walk and do everything like a normal person..."

At this point, the P.D. discusses the importance of motivation (getting pleasure out of an activity) as the key to O's use of both hands and her rejection of authoritarian prescriptions to the child to do one thing or the other. To put it in another way, she emphasizes the fact that O's progress is due in part to the incorporation of motor activity into play which is pleasurable.

Finally, Mrs. O speaks of an impending eye operation for O, but will wait until her husband comes from Hong Kong, so as not to bear this burden alone. Cueing in on Mrs. O's cultural concerns, the P.D. remarks that the operation "will not only help her vision but will help make her pretty, too." She validates Mrs. O's decision to wait for the operation until her husband's arrival "...not to have that tension all by yourself."

In the final interview, the P.D. presents alternatives for post-discharge follow-up referral: the OP program at IRM or a UCP Center. Since Mrs. O works, she is advised to select the UCP Center which provides transportation, whereas the OP program does not. On the other hand, Mrs. O is adamant that her child come to the OP program which provides intensive PT in addition to the educational program (whereas the UCP center does it only to a limited extent). She beseeches the P.D. in the following terms:

"...can you do me a favor...can you call my boss and tell him that it's necessary for O...ask him to give me two afternoons off, so that I can take her here and back."

The P.D. agrees readily that either she or Dr. G will place that call. She also offers to assist in payment of the taxi fare if it is needed. A recapitulation of O's progress ensues, Mrs. O placing, not surprisingly, her emphasis on "walking better," "movement of hands," "left leg looser."

Separation anxiety problems of the child have lessened:

P.D.: "I hear she's finally letting you work with her. Do you feel she's less demanding of you now?"

Mrs. O agrees with the P.D. and speaks about getting a bed for the child so she can sleep in her own bed instead of with her mother, which also implies the lessening of Mrs. O's separation problem. Mrs. O's decision is supported.

The P.D. asks Mrs. O whether she has noticed the more "organized play" of her daughter, but Mrs. O misunderstands (she has probably never really understood the cognitive component of play) and answers in terms of motor concepts (the child moves her hands better).

The P.D. brings up the subject of toys, whether Mrs. O can afford them and the possibility of borrowing them from the Infant Room. Mrs. O breaks down and cries. Mrs. O feels very alone, having no one to talk to. Over a two-year period, she has saved a large sum of money to pay for her husband's passage from Hong Kong to New York. All of a sudden, her husband stopped writing - she hadn't heard from him for several months. Mrs. O imagines that either he is in prison or he is dead. Although Mrs. O claims she has a lawyer looking into the situation, the P.D. offers the help of the Director of IRM who "knows alot of people in Hong Kong" and she adds "Maybe we can make some inquiries."

Mrs. O's parents apparently provide no emotional support to her:

"They have gone through a lot of difficulties. In his early years, my father said he went through a lot of difficulties, 'Much more than you do...so...'"

The P.D. finishes the sentence: "So don't bother me..."

She sympathizes with Mrs. O's predicament and again offers to help her if Mrs. O does not hear from her husband soon.

This is the final interview. We found out subsequently that Mr. O had indeed deserted his wife, which the P.D. suspected all along. The subject of toys did not come up again in the last interview.

The P.D., when asked to evaluate the effectiveness of her sessions with Mrs. O, felt that her counseling had been minimally successful during the child's in-patient stay. (However, many subsequently voluntary visits while O was attending a referral neighborhood Day Care Center with many Chinese children suggests that Mrs. O had assimilated more of the program's philosophy than had been originally evaluated.)

Family W

Family W is of upper socioeconomic status. Because of the nature of the father's occupation, which required a good deal of travel, the family settled in many different countries. Nonetheless, they have kept in touch with the Project Director, and, when in New York, bring their daughter to IRM for further consultation and examination.

For purposes of economy of space and the strength and uniqueness (in this sample) of the themes characteristic of parents W, we shall deal with the data thematically, rather than chronologically. We shall revert to a chronological order when writing about Family J, and then again treat Family T thematically.

Before describing the themes so characteristic of parents W, we should like to state that the interviews followed a standardized format (as with all other parents), so that goals of the educational staff for the child and goals of the mother were discussed. The P.D.'s role in enculturating the mother as to the behavior expected of her was enacted, specific guidance was proffered, observations of progress by P.D. and parents W were made, and the separation anxiety of the child was interpreted to assuage the parents. For instance, Mrs. W's goals changed, as did other parents', after a period of only a month in the program - in the direction of realizing the significance of interaction with materials, whereas she had only stressed walking and language in the first interview:

"Something which I realize is very important which I did not realize with any (of my children) is this constructive play. That's why I'm so keen to find out what the materials are."

The two themes on which we wish to concentrate are the mother's abysmal feelings of incompetence when enacting her role as a mother, and the father's intellectualization of his daughter's problem as characteristic of his coping behavior.

After 5 weeks at IRM, Mrs. W is as enchanted with the program as she is disenchanted with her own parenting behavior: the child understands more

"and I attribute it to the fact that she's got this concentrated care...It's good I come on a weekly basis because I certainly see the progress."

Mrs. W declares:

"I know nothing about children."

She explains that in her country servants bring up children and that in the United States 5 children are an overwhelming burden for her, she does not know how to care for them, babysitters are both inadequate and expensive, etc.

In the following interview 1 week later, Mrs. W again reiterates her feelings of incompetence and dependence on the P.D.:

"I feel like a duck out of water. I feel I should be told and told

and told... I want to make sure I don't forget anything you tell me."

A week later, in an interview with the master teacher, Mrs. B, Mrs. W declares:

"All this child thing (development) is very foreign to me. I feel I have to make a project of this, and if there's any literature I should read I'd appreciate..."

Mrs. B reassures her:

"You'll pick up a lot just by being here."

(It is not improbable that Mrs. W learns more from books than from live observation, in view of the fact that she spent many years at school studying for a Ph.D. degree in an abstruse subject.) Mrs. W is certainly ambivalent about how much she should do with her impaired child - she says that she has a peg board (at home) but "I would have to play with her." (To prevent siblings from interfering with the child's playing behavior). Other quotes, illustrating the feelings of ignorance, lack of confidence as a mother, feeling the burden this role imposes on her, and keen appreciation of lack of help follow:

"This is all so new. I'm totally ignorant. I don't know where to begin."

About the mess her child will make if she feeds herself, Mrs. W is upset in advance:

"In this country it's impossible with no help, or if it is possible, then you have to resign yourself to living in a pigsty."

"I'm a very nervous person and perfectionistic by nature, so it's very trying. But it's my choice (having married and had the children) and I wanted it."

"There's chaos at home. It's a sacrifice you make but when you live it day by day, it's very trying."

And finally, epitomizing her plight:

"I'm not the proper mother that I should be, doing what you do here and playing with her all the time... but it's just like pulling teeth to get me to be different."

In the final interview, after the P.D.'s explanation of how the child has changed and what to do, in her questioning Mrs. W if she understands, the latter declares:

"Oh yes, definitely. My problem is how do you take it from here? Do I feel I can carry out things I observe? Not really, I'm not a trained professional as physical therapists are. I may think I'm moving her legs but the fact is I may not do it the right way... I'm very sensitive to

W's moods. I know what to expect, but I don't know how to improve her. You need training to do these things."

Mrs. W's husband, on the other hand, is less concerned with what can be done to correct his daughter's condition than with diagnosis (including comparison with other children), etiology, prognosis, and the research process as carried out in the Infant Pre-School program.

Two days after admission, Mr. W already asks over the telephone questions which the P.D. explains can be answered only after evaluation and intensive work with the child. During the course of the first interview, Mr. W asks such questions as: At what level is she playing? Is this typical or atypical? Can we see some catching up in 3 years, 5 years, 9 years? What can we predict from your observations? Is hypotonia a lifetime condition? To all of which only tentative answers can be provided by the P.D. and Mrs. B, the master teacher. Other questions are: Is the physical lack of muscular tone responsible for retardation? Where does the child fit in comparatively? Are some children less capable? What will she be like 3 or 5 years from now? At the final interview, Mr. W is still not sure of the medical diagnosis or of its meaning.

All these questions elicit qualified answers on the whole: because it is difficult to say where the child will be x years from now. Some form of short term prediction may be possible after study. Rather than hypotonia being responsible for retardation, the P.D. explains that the neurological system is not intact, one facet of this condition being physical (lack of muscle tone), the other intellectual. She also explains that longitudinal data on each type of multi-handicapped child are lacking, so that long-term predictions cannot be made. She details the rationale for the research being carried out:

"It's exciting to us because there's a chance to look at these children in terms of our service program and analyze what really happens and try to understand why it's really happening... 5 or 10 years from now we might be able to do further projections..."

To Mr. F's questions about the certainty and meaning of the diagnosis "brain damage," the P.D. explains that this is an umbrella diagnostic concept, unenlightening, if not downright useless, because it does not provide an educational or emotional prescription or treatment. Too little is known about "brain damage."

In the final interview, in which little learning on the part of the father has taken place or perhaps it could be said that he's obsessed with intellectual understanding of his child's problems, the following interchange is typical:

P.D.: "She wants to speak. She has the thoughts that should go into speech, but she can't translate them verbally. She may do it much later. But she's processing directions better, and faster... We use terms "cerebral dysfunction," "brain damage," "lack of integrity of the neurological system..." Why I want to play down the labels is that they really don't mean a thing."

Mr. W: "I agree. Where do we go from here?"

P.D.: "We work with what the child has got - never mind the label."

Mrs. W: "... A hospital identified it as a muscular problem, not a brain problem."

P.D.: "Her most severe problem is expressive speech, not the thinking process - she plays constructively."

Mr. W: "Doctors, as a rule, tend to withhold information. Is it cerebral disability or brain damage?"

P.D.: "It's the same thing."

Mr. W: "W does not warrant this diagnosis. If it's a problem of communication of the brain to the muscles, she needs exercise."

P.D.: "That's what she's getting... educationally..."

Mr. W: "That makes sense."

P.D.: "I think one of the worst things is to make broad statements."

Mr. W: "Because it doesn't mean anything..."

P.D.: "That's right. It doesn't give an educational prescription, either."

At some level, Mr. W has finally understood - if only partially and perhaps temporarily - the confused semantics of a "brain damage" diagnosis. He responds to the P.D.'s last statement with the following remarks:

"What is the educational prescription for W at this point," which elicits psychoeducational assessment of and prescription for the child.

We can sum up this description of the major concerns characterizing Mr. and Mrs. W by stating that both parents feel their inadequacy keenly - Mrs. W on what to do physically and intellectually with the child, Mr. W in relation to his lack of knowledge about what is wrong with this child and the prognosis - but on an intellectual level (they are not experts) rather than an emotional one. The feeling of "ignorance" of the mother is not dispelled by the end of the program for her child. We would surmise that the father feels equally "ignorant" about diagnosis, etiology, prognosis, and queries the P.D. about the research process accompanying the service program, with the hope of getting a fuller understanding in time of what is deviant about his daughter and what caused her handicapping condition.

Family J

This case study is presented in great detail, to provide the reader with an idea of what really happens - the great diversity of themes in a long sequence of interviews (twelve). This case study is typical in its detail of all the other interview sequences with articulate parents.

No parent more than Mrs. J, who is Irish Catholic, reveals as sharply the process of change from negative to positive attitudes in the interface between the educational and medical institution (Infant Program) and the family (Mrs. J and her relatives). The generalized suspicion of bureaucratic institutions (of which Mrs. J's initial anti-institutional attitude is, with respect to the IRM, a manifestation - is suggestive of, and has been associated in the sociological literature with, a traditional, blue-collar or lower middle class, ethnically homogeneous tightly-knit family and neighborhood complex (Gans, 1962).

The separation anxiety of Mrs. J is extreme - also couched occasionally in almost 'supernatural' idiom - though it becomes manifest only around the end of the in-patient stay of her daughter, when she recounts her initial feelings. These were bolstered by the child's grandmother, who saw nothing wrong with the child and who influenced the child's father to take a similar attitude. From Mrs. J's report, her neighbors and friends did not understand either about the child's impaired functioning. From initial distrust, Mrs. J slowly began to appreciate what was being done with her daughter and to grow to like, and feel gratitude toward the P.D. and her staff.

In the course of the first interview, Mrs. J reports that her daughter was very upset when brought back to IRM on Sunday, which resulted in Mrs. J's feeling very upset herself. Goals are discussed. Mrs. J emphasizes speech:

"To communicate with us more; physical deformities wouldn't bother me as much as a mental..."

The P.D. states three basic assumptions of the program:

1. Motivation is the key to progress: "A theory of ours - a sound one with children - is you have to get them motivated to want to do it, you can't force them."

2. "I think we're pretty honest with each other, not pretending to do miracles."

3. "We need you just as much as you need us..."

Mrs. J talks again about her feelings of separation anxiety:

"I miss her terribly. I cry. But I'm a religious person. I trust in God so much, that and medicine."

Mrs. J and the P.D. discuss a recent parent meeting with Mrs. J's husband

attending and which both of them found valuable.

Mrs. J expresses fear of the coming evaluation and meeting with Dr. G. The P.D. tries to reassure her that nothing will come out that Mrs. J hadn't known previously.

The P.D. makes a very ego-supportive comment:

"Some parents are more likely to describe their children as they are because they've had more children and they can compare them. It's not like having an only child. Your first remark to me was, 'compared to my other children...' What do you think we do here? We do the same thing, except we have more specialized knowledge and hopefully, we know what to do about each area (of development)."

The P.D. and Mrs. J speak about possible etiology of J's brain damage - inheritance, older age of mother, pregnancy complications, etc., without, obviously, coming to a conclusion.

Mrs. J ends the interview: "I'm delighted. How many parents have the chance to put their children here! I've been fortunate in this."

(Her fear and distrust of the program - she is after all ambivalent at this point - do not come out until much later in the interview sequence.)

At the second interview, the P.D. asks Mrs. J whether she has seen any changes in the child. Mrs. J responds with a comment made by an older sibling of the child, that the latter has made progress in alertness:

"She seems more alive, Mom."

Mrs. J again speaks of her separation anxiety:

"Sunday night is hard for me: I leave part of me here with her;" yet stressing that another sibling told her that "It's the greatest you can do for her, Mom."

Mrs. J says: "I was glad to hear that."

The P.D. is immediately aware of the cohesiveness of the family:

"Your children are very involved with her," to which Mrs. J replies: "Oh, they are."

The P.D. supports the role of Mrs. J's family as better observers of change than the professional staff of the program, because they see J at intervals:

"Your son would notice more because he's not with her every moment. It's hard to see changes daily for us. You can see it, or your husband, or your son on weekends."

Mrs. J berates herself for having felt lethargic over the weekend, yet knowing she should be stimulating J in one way or another. The P.D. is very supportive and tries to dispel any feelings of guilt:

"You don't have to put yourself under that kind of pressure over the weekend. We're doing it all week long. You can enjoy her as a mommy; you're not a teacher. If you want to lie down and she's near you, this is fine..."

The P.D. and Mrs. J exchange observations about the child's walking, play activities, and the materials she uses. Mrs. J plaintively says:

"I want her to be able to express herself."

The P.D. refocuses the dialogue on the motor area and states PT goals, which, when achieved, will result in the child's ability to move and get interested in various activities.

In the third interview, after the exchange of information about the affective and language development of the child, the theme of Mrs. J's separation anxiety reappears:

"I feel like a part-time mother with her, leaving, coming back."

Then she switches to comments about the improved functioning of her daughter.

The P.D. gives Mrs. J specific guidance on letting the child communicate her wants instead of anticipating them:

"With a family as large as yours and with the children as loving as they are, the tendency is: 'This is the baby who is so slow; let's all give her everything.' It's the worst thing. Let's make J want it.... It won't help the children if out of love for her or compassion we don't give her the chance to tell us what she wants.... When a teacher sits back and ignores her, it's not ignoring her -- it's a plan that Mrs. B. wants her to initiate something herself. It's a much more subtle kind of teaching."

The P.D. relates to Mrs. J her observations of the child's greater involvement, responsiveness and awareness, and emphasizes her recently acquired vocalizations.

The parting advice to Mrs. J is:

"Tell the other children to try to make her communicate -- even pointing or grunting."

The fourth interview, only a few minutes in length, is revealing of another physician's reaction to seeing the child:

"He was pleased: 'It's like a birthday for me when I see her walking!'"

Mrs. J's husband also said that in the last few days "she's been alive really."

The P.D. and Mrs. J share with each other their joint observation that J is settling well in the program and that her previous separation anxiety has diminished.

By the fifth interview Mrs. J speaks of two of her teenage children, who have made observations about J's animation and alertness over the past weekend, and, who, in their mother's estimation, are "more qualified to say," than she.

The P.D. demurs: "You're qualified to say, but what interferes (is) ... you're seeing her every day. It's hard to see changes."

Mrs. J: "The kids said: 'She never said "no" before,' and I didn't realize it."

P.D.: "You sometimes forget what a child didn't do because you're so involved."

The separation problem arises again, and the P.D. comments:

"I appreciate your feeling about wanting her back and I appreciate your feeling that you've seen enough change to warrant this. The child is not upset here; you are more upset about her being here and you still are more than she is. She's being cared for lovingly, and I think she's making gains."

The interview ends with the P.D. and Mrs. J exchanging information on the child's speech development, with Mrs. J saying wistfully:

"I wish she'd say her name when I ask her what her name is," to which the P.D. responds:

"That's later -- 3-4 years old."

As the fifth interview ended with observations in the language area, so the sixth interview begins similarly. Mrs. J, who was not aware of the gains observed by her older children, says that she is pleased now.

The P.D. comments: "Last week, separation was more than the benefits. And the scale has to be balanced. Parents do go through this and you're very close to her."

Mrs. J reports that she got a list of toys for the child and that, although she has not bought them yet, over the weekend she gave her child cereal bowls and containers to play with. The P.D. suggests improvised play with the percolator coffee pot, which can be taken apart and put together again and is "the best toy, a puzzle." According to her, pots and pans have a nice texture, nice sound, and come in different shapes. "They have all the things built into educational toys."

In the seventh interview, observations are exchanged about the child's speech development, work with materials, self-assertion, and walking.

When Mrs. J reports that her daughter does not like finger painting, (Mrs. J doesn't like "messes") the P.D. explains at length the importance of exposing the child to different textures:

"It's terribly important, since J avoided contact with things and wasn't playing that much... How is she going to learn what's soft and gooey... That's an appropriate activity these children should have - whether sand, mud, or soap suds. The child has to know the sensation of different materials on the skin."

Mrs. J: "I don't like a texture that's hairy..."

Play-dough is suggested (for the 5 year old sister of the child) and that J be encouraged to touch the flour (smooth) and salt (rough) which are ingredients of homemade play-dough:

"This is part of their education."

This interview ends with Mrs. J stating that she will borrow toys from the Infant Room for use by J over the weekend and that she will buy the toys recommended by the P.D. at the store.

The eighth interview begins with a statement by Mrs. J that she has gone to the store and bought a form sorting box. Mrs. J is anxious to get her child discharged and asks: "Do you think J is about half way through?" The P.D. at this point is unable to predict the discharge date. She discusses the out-patient program as a follow-up referral rather than a neighborhood school program, because of the high teacher-child ratio.

Mrs. J reports her husband's observations of their child:

"She was really a live wire this week.' I was glad..."

The P.D. comments: "I think it's harder for fathers to articulate what the problem is. They don't quite see it.... You and I have been talking constantly (together)."

Mrs. J: "You see, his mother doesn't think there's something wrong with her. And she can't upset him (Mrs. J's husband)."

P.D.: "It's like putting your head in the sand. That makes it hard for you. That happens with a lot of grandparents by the way."

Mrs. J. indicates that her mother-in-law "likes me a lot but rubs me the wrong way... She could be cooperative."

And she adds that friends and neighbors do not understand either:

"I tried to explain to a few people and they don't seem to understand just what's what."

The P.D. promises (upon her request) to give Mrs. J more brochures related to cerebral palsy.

The ninth interview begins with Mrs. J's report of the validation of change in the child by Mrs. J's sister and her 18 year old nephew. The aunt of the child said:

"She's terrific, she looks fantastic. She's playing peek-a-boo..."

Re: Discharge date, probably because she has finally realized the progress made by her child at IRM, Mrs. J says:

"I'm not pushing (now) for her to go home."

Yet she relates that her other children have been asking questions about how long the child is expected to remain in the hospital.

Observations are exchanged about the child's "floppiness" or hypotonia and her weight, which adds to the motor problem.

To the P.D.'s question in the tenth interview about Mrs. J's observation of her child's play activities, the mother responds:

"She was pretty good during the day, not bad with the playing at all. I can see what she has learned since she came here... When she looks at a thing, she stays with the toy, she seems to do it in a fashion like she does here."

Again the separation of the mother crops up:

"She was very happy when she came in here. I thought to myself: maybe they have more to offer than I have."

P.D.: "She's become comfortable here. Where can any parent spend that much time with a child?... No home can give that much intensive attention. No child needs this constantly. You have ten children, household chores to do..."

Mrs. J: "I find I spend more time with her here than I do at home."

P.D.: "When she settles in at home, hopefully she'll be carrying some of her 'learning' with her. Your job will be as a mother. And recognize that you can't give all of your time... However, she's going to be asking more of you and the other children.. at a different level."

Mrs. J: "She has a pretty temper and she hits when they tease her."

P.D.: "You used to describe her to me as 'too good'."

At this point in the interview, Mrs. J makes her real initial feelings toward the P.D. manifest, as well as her later satisfaction, and we quote from the dialogue between her and the P.D.:

Mrs. J: "Mrs. G, I felt at the beginning you were taking her from me. You were taking my child. Like I was giving you so much. That's not what I mean, either. I was giving you my daughter, part of me. I felt like I was doing you more of a favor than you were doing me. That's not the word for it. But I'm so glad I was able to be part of it (the program)."

P.D.: "It's very good for me to hear you say that because I knew how upset you were."

Mrs. J: "I felt terrible about it..."

P.D.: "And it was always a risk for us, knowing how deeply you feel for J, to take J based on our belief that we could help her. I had confidence that she could cope with us. We hoped her mother would adjust to it. You are a very close family."

Mrs. J: "I felt terrible. The opposition of people - my mother-in-law ... My father-in-law understood it."

Mrs. J: "I'm so glad I was given the opportunity."

P.D.: "It helped J, even if it was hard for you."

Mrs. J: "I think so."

Mrs. J: "She needed an educated approach... I'm very pleased. I'm a religious person. I'm so relieved I was sent by Dr. L to Dr. G. I'm delighted, believe me. I see the difference in J - she's enthusiastic, plays with dolls with her sisters."

P.D.: "She's more of a girl..."

Mrs. J: "She's doing things."

P.D.: "And she's interested, and fussy, and angry - some sort of temper is good and what you wanted."

Re: The discharge of the child.

Mrs. J: "I'm very pleased with J. My (other) daughter said: 'It's too bad you're leaving such a nice place'."

P.D.: "We'll keep in contact, though. I hope we can start an out-patient program in the fall... in J's case, I'm not worried. With the stimulation by your children - you're less protective of her than you used to be and you know what we do here..."

Speaking about the program in general, Mrs. J says at the end of the interview:

"I feel very pleased. You have no idea."

In the eleventh and final interview, Mrs. J expresses her feelings about

having the child home again:

"I thought she was about ready to come home, but by the same token, I was sort of sad. Maybe there's something else J could learn, maybe it was a little swift. But maybe you got her to a peak. But she's more involved at home. She sticks to things. She won't let me hold her for any length at all. She pushes my hands outside."

Observations are exchanged: The child is more self-assertive in contrast with her previous passive behavior. A nice detail:

Mrs. J: "The child brought her father's slippers to him in the living room, addressing him as 'Dada'."

At Mrs. J's mother-in-law's house, the child explored the piano and started playing. She communicates better and her vocabulary has increased:

"It seems spontaneous." (All observations made by Mrs. J)

Mrs. J: "I'm very pleased with the program so far, really I am."

Asked if her goals were realized, Mrs. J answers in the affirmative.

The evolution of Mrs. J's feelings about the program and the P.D. are recounted in the following interchange:

P.D.: "You were a reluctant mother at first - so concerned."

Mrs. J: "I had the feeling you were stealing my baby."

P.D.: "In a sense we were."

Mrs. J: "I wanted it, but was afraid of the emotional impact on her - the feeling I was leaving her. For the first few weeks I felt I was doing you a big favor."

P.D.: "By giving us J?"

Mrs. J: "That's the feeling I had."

P.D.: "We were telling you we were taking your child to help her in a way you couldn't."

Mrs. J: "That's right. It was terrible. She was gone from my house."

P.D.: "Someone else was taking over what you should be doing...?"

Mrs. J: "I look back now. I can't explain it. Why did I think like that? Why did I feel like that?"

P.D.: "I don't think it's uncommon thinking."

Mrs. J: "I wanted her here."

P.D.: "You were torn... it's against part of you."

Mrs. J: "Guess it was. I was doing the right thing, but had a little bit of depression about it.... No. I had a fear; I can't tell you. You were doing it."

P.D.: "Because I was the one you had contact with. I hope that's it. Maybe it was my manner.... I think we always have to prove ourselves to parents."

Mrs. J: "By the end of the first week I was convinced. I can't explain it. My feelings were so mixed. As I said, you were the culprit."

P.D.: "Only one week?"

Mrs. J: "That's it."

P.D.: (teasingly) "I can't be that threatening, then. It must be hard to turn the child over: 'Are they really going to take care of my child?' And I think we do. We have to prove ourselves to parents that we are caring, that this is not just a study that we're concerned with, that we care about the children."

Mrs. J: "Also, J wasn't your first (child in the program). If she were, I wouldn't have let her come at all."

Sibling cohesiveness in Mrs. J's family is again stressed:

Mrs. J: "They're very close to the child. They come in and check her at night."

Nonetheless, her children feel that Mrs. J is overprotective and the P.D. seizes the opportunity to query Mrs. J's present attitude toward her impaired child:

Mrs. J: "My older boy says I'm an overprotective Mama."

P.D.: "Some parents when they leave the program have the feeling they can't go on in the same way. Do you have any feelings like that?"

Mrs. J: "I saw some of the approaches you used and I will be able to work with J further with them. I'm constantly talking to her."

P.D.: "You picked up a lot of techniques, so it doesn't leave you feeling distraught."

Mrs. J: "No."

The P.D. suggests that Mrs. J assess what her daughter got out of the program and the latter complies, speaking of the child's gains in speech and walking

(here, as in the initial interview, Mrs. J emphasizes language as her first priority).

The inquisitiveness and possessiveness about things reported about the child by Mrs. J are interpreted as normal and positive behavior by the P.D. The final remarks to Mrs. J follow:

"You don't have to give her (only) structured activities. The more she touches and feels, tastes and smells, the more she'll enjoy all these things. And, as you do now, label these things, so she knows that things have names. I think you are on the right track."

As Mrs. J attempts to thank the P.D., the latter quips:

"No, don't thank me, because I took your baby (joint laughter). I'm glad I took your baby, because I gave her back to you healthier."

The P.D. underscores the importance of parents communicating their feelings about the program, their anxieties, to her so that she can be more sensitive to their feelings:

"You'd be surprised, it really helps me hear each of you... If you know this is a family's reaction, it tells you: Beware of this. It makes us more sensitive to what you're going through. No matter how sensitive professionals appear, we can't put ourselves in your place unless you communicate with us."

Mrs. J: "Time was when I didn't want to."

P.D.: "We learn from parents just as much as they learn from us. Youngsters mean a lot to us. We invest ourselves - we see them grow."

In a post-discharge interview, Mrs. J reports her feelings of inadequacy as a parent, compared to the role enacted by teachers:

Mrs. J: "You pick up little things done in here, different things I've seen in here and I've gone home and I told my children. I think we can build on it. I pick up more through the observation room. I can watch J and the other children. In the room I feel..."

P.D.: "Like you're not needed?"

Mrs. J: "This is me. I feel a parent can't do enough when compared with what the teachers can do."

Nursery school plans are discussed and a Bronx school supervised by the Bank Street College of Education is recommended.

During one of the voluntary social revisits to TRM 3 years later, Mrs. J still praises the infant program, but also still harps on her (past) feelings toward the P.D.:

"To me you represented... You were harmful. You just had that

look... You were taking my child from me."

P.D.: "You got over it."

Mrs. J: "I thought it was your fault. You represented a terrible monster."

Family T

The interaction between the P.D. and single male parent T, who is Puerto Rican, consists of ten interviews. Instead of treating these consecutively as wholes, we shall trace the development of the major themes, one by one, through the sequence of interviews. Mr. T is a student. He lives with his mother, and the family receives public assistance.

Separation Anxiety

The quasi-universal theme of separation problem anxiety of Mr. T's child comes up immediately in the initial interview. Apparently, the P.D. reports, he cried only a little when his father left and "settled down very easily, eager to relate to all of us, being warm, very friendly, very happy..."

In the course of the second interview, in response to Mr. T's report of crying and fatigue on the part of his son, the P.D. explains that the boy had "a delayed reaction" to separation and reassures Mr. T of the normalcy of this anxiety:

"It's because he cares for you. It's a positive thing. If T didn't go through this, as I told you, I'd be worried. He was too comfortable settling in. He was so excited by the people - by the toys. Now he suddenly thinks 'What did my Daddy do? He left me here.' This will go on for a couple of weeks and this too will stop... We've seen it with all youngsters. It really does pass."

By the fifth interview, Mr. T reports that his son was in a good mood over the weekend:

"The first week he wanted (just) to be held. Now he's more independent."

P.D.: "Now he's not worried..."

Father as Participant in the Program

In the initial interview, Mr. T expresses his desire to come and visit his son at IRM "everyday this week, because I'm not in school yet." The P.D. agrees, asking him to come after 4 p.m., so as not to conflict in his participation with other parents, whose participation day (9:30 a.m. to 4 p.m.) the day might be.

In the initial interview, no doubt, because the P.D. is dealing with a male parent, and not a mother, she emphasizes the norms of participation for him very strongly:

"I hope in our conversations together you tell me what changes you notice after he's been here a week or 2 weeks... if he does this more, if he does that more... We'll be talking about little things that he's doing that have changed. And we'll capitalize on what you tell us and we hope you capitalize on what we tell you."

Throughout the in-patient stay of his child, Mr. T takes very seriously participation in the infant program one day a week, as well as the weekly meetings with the P.D.

A lapse occurs around the time of the sixth interview.

Under the P.D.'s prompting, Mr. T admits that he forgot to take a toy for his son's use during the weekend and that he forgot a parent's meeting which had been set up for the next day. By the ninth interview, Mr. T has again taken the role of a student and he comes to visit his son after school at 6:30 p.m.

Parental Goals

As far as the father's goals are concerned, walking constitutes his priority. Otherwise, Mr. T feels that "he's kind of slow."

P.D.: "What makes you feel he's delayed?"

Mr. T: "It is my own assessment. I don't know too much about children, but he's 2 years old now and he should be walking."

Secondly, Mr. T is aware of his son's retardation in speech development, but he qualifies his statement by saying that he's more concerned with the child's ability to walk.

On the other hand, Mr. T qualifies the negative statement about his son's functioning by the following remark:

"I think he's pretty smart. He has an awareness."

In the final interview, Mr. T recounts his initial lack of understanding of the functions of play and the educational implications of interaction with materials. His understanding has completely changed:

"I was really not concerned. I didn't know the meaning... I wasn't aware that these toys can actually teach him anything. Toys are for playing, this is the way I saw it. I didn't think they were going to be instructional."

The P.D. makes him see that T "is on his way," the foundation has been built, and "you're his father and we are not."

Observations of Gains in the Child

The P.D., in the course of the second interview, communicates to Mr. T some of the advances his child made in interaction with materials:

"He does very fine-size discriminations, which is unusual for his age... He's not as chaotic in his play as when he first came in. He stays much more focused."

A variety of observations re: growing independence of the child, playing

by himself, playing with peers in the Infant Room, exploratory activities, speech development, are exchanged between the P.D. and Mr. T in the third interview. The P.D. cautions that:

"He gets most pleasure out of people. But also important are objects and what you can do with them."

Mr. T declares he is very impressed with the PT exercises his son is receiving. And he reports that at home he tries to walk with the child - we recall the emphasis Mr. T placed on the motor area in the first interview.

Mr. T for the first time mentions a play activity of his son: finger painting. The P.D. does not lose the opportunity to instruct T's father about its significance and the general philosophy of the program:

"There are many facets to finger painting - sensation, power to make design, color, texture, relationship to others (children) doing the same thing - a learning experience, sensory experience that are very important - the experience of color... then you can introduce labels... you can match colors or shapes..."

In the fourth interview, the P.D. asks Mr. T what gains in language the child has made. He contrasts language behavior at IRM with home, to the latter's disadvantage. Mr. T wonders about whether his son can "pick up more than one language" (this is discussed on page 26, where the focus is on the theme of a bilingual home).

In the fifth interview, Mr. T reports that he put T in a walker over the weekend and:

"that is he'll go into rooms and lock me up."

The P.D. remarks that: "The whole idea of opening and shutting is an intriguing thing (to children)."

She also reports an observation congruent with that of Mr. T:

"He used the form box cover as a door. He's just interested with the fact that he can close off space and open it up and control what happens."

The first part of the sixth interview is devoted to T's attempts at walking. (Father declares his fear and tentativeness).

P.D.: "This is going to take time. He's just not sure of himself... It's not just a matter of being physically able, but of being entirely emotionally ready to have (enough) confidence..."

Mr. T replies that he's satisfied with the explanation that Dr. G gave him:

"He didn't guarantee that T would walk within 3 months time."

P.D.: "He's doing beautifully in the educational program."

In the seventh interview, the following interchange takes place with respect to T's interaction with materials:

Mr. T: "I took some toys with me. T was disinterested. I tried to encourage him."

P.D.: "These toys have a limited use - some children resist them. It may not be challenging enough. Try a truck, pegs, extend his play, really. The form box can be used as a house. T may prefer water play or magnets, or flashlights. They're just as useful. He could pour water in different containers. You have to make the possibilities. That's what teaching is. Toys can be extended in many ways.... They bring something else or the child brings something else! A toy is designed for specific reasons but is used by teachers in different ways or children suggest something else. When T got a flashlight, he did what doctors do in the morning - to check his throat: it went to his mouth. He put the stethoscope in his own ears - that's good: he understands."

In the eighth interview, the P.D. reports both that T is on the verge of being toilet-trained - and that he did "excellently" during his first periods in the Pre-School program - exploring the nursery school room. The P.D. proposes placing the child for an hour everyday in the Pre-School program (older group of children) for the next few weeks, because that group of children have more expressive language than the Infant School group and would stimulate T's emerging language.

In the final interview, the P.D. reviews the gains made by T in the area of interaction with materials:

"Do you remember how he used toys when he first came in?"

Mr. T: "Yes, he just picked it up and threw it."

The P.D. then explains the multiple - including the unanticipated - use of material:

"Sometimes children will take one material that is designed for something else and make it something they're interested in - just like the form box. T got bored with using it as a form box and decided to use (the cover) it as a door."

The P.D. shares her observations of T's behavior with his father:

"T is picking up size and shape discrimination very rapidly."

She suggests that Mr. T play with T during weekends, 10 to 15 minutes, with toys borrowed from the Infant Room. T should be encouraged to bring his own ideas to the use of toys:

"T can be a creative little boy. We want him to do that as well as use materials for purposes built into them."

Mr. T confesses to not being aware at admission whether the child was up to age level or not "in other things beside walking."

P.D.: "You now realize he wasn't at age level?"

Mr. T: "Yes, but I couldn't put my finger on it."

In her final remarks, the P.D. points out expressive language (two to three word sentences) is coming but that the child blocks people when he chooses not to hear.

Specific Guidance re: Interaction with Materials at Home

When the P.D. brings up the subject of materials to which the children are being exposed in the initial interview, Mr. T is slightly embarrassed that he cannot afford to buy his son all the toys which he has seen in the Infant Room. The P.D. supports him, by making plain that no parent can provide the variety of toys available at IRM, but that Mr. T can buy his son specific toys that the boy is interested in.

In the fifth interview, it is suggested that Mr. T borrow some toys over the weekend, as specific ones are recommended by Mrs. B, the Master Teacher. She suggested that T play with containers of different sizes and engage in scooping - "the kind of thing he can do with you, with your mother - cooking." This may teach him the idea of different sizes. The P.D. stresses the quality of sand - texture, quantities of the material. She also suggests he play with soap suds and finger paints, "All cheap activities." "Water and sand are very good (play materials) for the children." She also suggests giving the recipes to his mother for making play-dough out of flour, salt and water.

Pre-Discharge Assessment of Child by the Project Director

Toward the end of the child's in-patient stay, in the eighth interview, the P.D. assesses the child as follows:

"Our big job for this boy is to get him an education. He's got the mind for it - the personality for it. He's got the will to learn. If you give him materials to play with, he'll give up oral behavior. If you give him a constructive thing to do, he will not be destructive. He can learn to say 'I don't want it' instead of hitting a child... which again is growth. He has become less fearful. He's a cautious walker. He's going to be a cautious little fellow. He makes good judgements as to what he's able to do. Some children don't know what they can do. They don't know their limits. He's going to go slow in what he's going to do."

Mr. T: "He's so afraid to go outside."

As Mr. T questions the durability of the gains his son made due to the program, the P.D. reassures him - based on referral to OP program at IRM.

"You can feel more secure now with the help of the out-patient program. He likes what he's doing. He likes himself. He's just having a good time. We think he's a very warm little boy. And he must have gotten it from you (the warmth). He's a most unusual and charming little boy and he's got alot 'on the ball.' We're going to miss him, because he's been lots of fun. But we won't miss him because he's going to be back (soon)." (Out-patient program).

The P.D. asks Mr. T whether he feels insecure about having T home again and giving him the stimulation he needs. Mr. T seems to feel that he cannot duplicate the rich environment of the Infant Program.

Mr. T: "He was very attached to my mother and now he's more attached to me than my mother."

P.D.: "Because you've been part of the program?"

P.D.: "You think this would have been as effective for T if he had just been an out-patient?"

Mr. T: "I don't think so. You actually brought him up to his age level."

P.D.: "It would have been a burden for you, too..."

At the end of the fifth interview, the P.D. suggests that Mr. T act as interpreter for his mother on the value of interaction with materials of which the child is capable:

"Things are important for his growth... She is the one who feeds him and takes good care of him physically. There is another part (of him) which is important."

In the sixth interview, the P.D. asks:

"How does your mother feel about T? Does she see changes in him?"

Mr. T: "I've just been explaining to her what T is doing here. I don't think she's been aware of the significance of this institutional life. She would just like T to get up and walk right away, just like that, without any trouble."

P.D.: "Can you get her to understand the (medical) problem involved in his walking? That it's not just a question that he's a little slow... that he's had some change in his development compared with other children. Do you think she doesn't want to understand it or do you think she really is trying to face it with you or is she more comfortable pretending it doesn't exist?"

Mr. T: "I think she feels more comfortable to think it doesn't exist. She feels that at any moment T can just get up and start walking. She's talked about a couple of dreams she's had: she sees T walking."

P.D.: "It's wishful thinking... it's understandable. You wish hard enough, you may think it might come true and I guess..."

Mr. T: "I know that it's just not overnight..."

During the course of the seventh interview, the P.D. suggests again to Mr. T that he bring his mother into the program, to which Mr. T replies that he would do his best. (The grandmother does come on several occasions).

Interaction with Materials

P.D.: "You know he can learn from sand and water, too - all kinds of objects. He looks carefully. You can take a lot of cues from this little boy about what interests him. We'll watch with you and, if we think there are other kinds of activities, we'll tell you."

Although subjective feelings of inadequacy remained for a time - it was the unanimous opinion of the P.D. and her staff that Mr. T was a sensitive and motivated observer, participant, and learner - with respect to the program. His response to the Parent Satisfaction Questionnaire showed that in the meantime he had developed a sense of competence in dealing with his son.

Post Discharge Referrals

The question of a good referral for T is discussed as early as the fourth interview. An ideal program would be one which includes children who speak more fluently than T does.

"I don't want him just to stay with his grandma at home."

She suggests a United Cerebral Palsy program which has Spanish-speaking mothers, and where, therefore, T's grandmother would not feel as alienated as she probably would at IRM. She advises Mr. T that the grandmother should know what to do with the child when he, the father, is not there.

In the course of the eighth interview, the P.D. delays the discharge date, because "PT feels he needs more time to feel sure of himself... We now have a walking boy." After discharge, T is expected to come to Out-Patient twice a week with periods of additional PT and the P.D. predicts that:

"Once he's walking solidly enough, he can be in a regular nursery school because he would not be too vulnerable to kids who are racing around - so he doesn't sit with grandma all day."

She suggests to Mr. T that he visit and observe programs at neighborhood schools.

"You've learned enough about our educational program to know what's good and what's not good. Go over and look around. See how many children are in the program, what kind of teaching is going on."

In the seventh interview, the P.D. recapitulates the gains T has made at IRM, but points out his physical problems compared to "normal" $2\frac{1}{2}$ -3 year old.

"The main thing is his having enough physical strength to keep up with children who are moving faster..."

She suggests (for the future) the Brooklyn College Early Childhood Center which has a good teacher-child ratio and a sound educational atmosphere.

In the next to final interview, talk centers again around Out-Patient program and referrals after that. Mr. T, although he is a student, declares that he has time to bring his son in for Out-Patient school and physical therapy twice a week for the time being.

Final Verbatim Interview with Mrs. JJ - Date-11/17/74

P.D.: We want to give JJ time to get settled so that we know he's used to being home - before coming back here to OP. When he comes back - he'll understand that it's just for a visit, for school, some therapy and go home with Mommy. He will be discharged December 3. PT and Out-Patient school will work out the schedule. You sound like you're tired. Anything wrong?

Mrs. JJ: I guess it's all the excitement and now... coming home.

P.D.: Does it worry you?

Mrs. JJ: A little...

P.D.: In what way?

Mrs. JJ: I'm not worried about him. I'm worried about me. I was going to try not to go back to the way it used to be, holding him all day. (In a previous interview, Mrs. JJ had revealed to the P.D. her habit of holding the child all day long while cooking, washing dishes, etc.) He was playing this morning when he was in PT. D says when she works with him in PT, he works great with her. I work with her, he won't do anything. She says she has that problem a lot. Children don't want to work with their mothers. Their mother is a mother. I noticed in the past few weeks - I never really noticed it before. He's in here, to me he seems to act more mature than he does at home. When we're on our way home, that's it - head down. A lot of things he does at home, I've got to give him credit. When I want to show him something, as soon as I've showed it... this weekend, though, I brought him a wheelchair from PT and I bought him a puzzle. I was out 4 hours and he was in the wheelchair and he was so good. That's the first time I ever took him anywhere where I didn't have to stop. He didn't cry at all. I have a stroller for him... he keeps sliding off... and I took him out in the wheelchair and he was great - he didn't cry once. He watched everybody, you know? He sat up the whole time he was out. His head wasn't down once. And I had to pull him up. Usually he kept smiling. I didn't have to do anything here. He was great.

P.D.: You attribute it to the wheelchair?

Mrs. JJ: I think he's associated the wheelchair with the hospital.

P.D.: That was his grown-up behavior.

Mrs. JJ: He will be good, even in the house. This weekend - that's it - he's not going to be held. He was great the whole weekend. I thought he was going to be cranky because he was cranky here the first week or two. He wasn't cranky that weekend or anything. I think a lot of his crankiness is from the valium. They give valium early in the morning and then 3 in the afternoon and then at night. I give him the valium at 12 in the afternoon, at around 9 at night. That night I don't have problems. I put him to sleep, that's it. So I'm not going to wake him up at home to give it to

him at 9:00. By 11:00 a.m., he starts getting cranky. I give him valium. In the afternoon, he's great.

P.D.: So your timing is better, then.

Mrs. JJ: I think too much of a span exists in between 8:00 in the morning and 3:00 in the afternoon - 6-7 hours.

P.D.: The wheelchair has been ordered. It will take some time to get it.

Mrs. JJ: I can borrow one.

P.D.: That's what I suggested at the meeting this week because he does better in a wheelchair.

Mrs. JJ: The umbrella stroller is too narrow, he cries after awhile.

P.D.: Can we do a little bit of going back for the record? When you came in with JJ, what did you expect to get from the program?

Mrs. JJ: It's hard to say. I expected a lot of other things and I got a lot. I didn't get what I really expected, but I'm happy with what I got. After 3 months here, he's sitting up all by himself and he's been using his hands already and I figure - I expect a miracle - that's what I do, but he's still doing just as good. He's not doing what I expected. I know he understands whatever I tell him. Before I didn't think he really understood. But now I know that he does.

P.D.: In what way? What are the changes - more concretely - that you see?

Mrs. JJ: I really... my feeling was that he was still like an infant. If you tell an infant not to cry, a baby doesn't really know what you're telling him. But I think now when JJ screams - it's temper screaming, not crying. I pick him up and baby him. But now when he starts screaming like that, I tell him: "No, JJ, stop..."

P.D.: He's taking directions?

Mrs. JJ: So now I know how much he understands, I can work with him a lot better. He's not sitting a lot but he's sitting a lot better. His head, to me, is almost 100%. This weekend he showed me if he wants to keep it up...

P.D.: It's a question of his will?

Mrs. JJ: Right. A lot of my friends tell me they notice a big change in him, because they haven't really seen him at all. When I was out with my girlfriend shopping, she couldn't get over it. She's the only person that took almost as good care as I do... she noticed it right away.

P.D.: What did she see as the difference?

Mrs. JJ: She thinks he's doing fantastic. He sees everything. She pointed it out to me how he used to be, the way he holds his head up and he's not sitting on his back, he's sitting on his rear. He was sitting on his spine. But now when he's strapped in, he's sitting straight.

P.D.: You're talking about his understanding. What has changed?

Mrs. JJ: It isn't as though I wanted it that way but I thought he was too young yet. I never compared him to any other children. And most children his age are talking or almost talking, so they should understand what we're saying. But I never gave him a chance. I never sat down and said: 'We're going to eat, J. Do you want to do this?' Now I do it, I see I get a response from him.

P.D.: How do you get his answers?

Mrs. JJ: If he wants something, he gives me a big smile. He makes some kind of little sound with a big grin. His no's - if he doesn't want something, to me he says, 'No.' He's starting to realize that that's a word he's saying. If he doesn't want to eat, he'll say 'No, no.' He gets stiff, too. If he wants a book, he lets you know. He's got his eyes on the book. He doesn't want you, he wants the book. It's not you anymore (referring to herself).

P.D.: So he's able to communicate to you more clearly what he wants, telling us about language. Do you see any difference in his use of toys or playing? Do you see any difference in your knowledge of toys and what he should play with?

Mrs. JJ: The toys he used to have are no good. I got him a few new toys - simple little things: You put on a peg. And I got him a little puzzle. It keeps his interest. I could sit there and he doesn't start crying right away. I give him mechanical things: he'll look at it two seconds and start crying. Now you give him something, like his hand... I give him an ice cream cone and he got a little ice cream in his mouth. Yeah, he made a mess. But he... used two hands. By the time he finished it, there was no cone left. He squeezed it a little too tight, but he was looking at it and biting it and he loved it. As soon as he realized the taste was good, he brought it right to his mouth.

P.D.: We'll have to work with ice cream cones.

Mrs. JJ: The only thing I don't give him is lollipops.

P.D.: Do you think you've gotten information about the kind of toys to give him?

Mrs. JJ: I think so. Most of the stuff they have around the Infant Room - that's the kind of toys now that I look for. And they're really simple, little nothings, you know that really amuses him, which amazes me. I'll go out and get all these rare, rare looking toys that do amazing things and he doesn't like any of them. And pegs and blocks and things like that is what he really likes.

P.D.: Yes, I think that parents in general tend to select toys for themselves, or the things that intrigue them and we're intrigued by different things. One of the hardest things is to get the parent to make a judgment of how the child gets satisfaction.

Mrs. JJ: And I think really I know by now because I remember when I was a kid I always wanted a baby doll and kept getting grown-up dolls to dress. It's the same situation here. The toys I got for him, I enjoyed them - they were too grown-up for him yet.

P.D.: Yes. I also think you have to know what hopefully he can do with them with your assistance. Even if he is not doing it alone, it's an accomplishment. I think one of the problems with mechanical (toys) particularly, is that a child has no effect on it. It happens... but I didn't do it. Even knocking over a tower - he feels that he did it. (JJ cannot grasp objects - or move arms - severely physically impaired).

Mrs. JJ: I got building blocks for him. He likes this, he knocks them over. With pegs sometimes I take the wrong color and put them all in another color. He likes those kinds of things. The puzzle he likes. The puzzle I got him isn't really what I wanted. I wanted whole pieces like a cow. And this one is - it only has four pieces to it.

P.D.: It's too hard.

Mrs. JJ: Yeah.

P.D.: You can go back to those simple pieces, where there's one for each part. And even if it doesn't come with handles, take wooden spools.

Mrs. JJ: I told my husband. He's a carpenter by trade.

P.D.: Just drill a hole and put a peg (spool) in it for a handle. It's really more important to get the one piece in one place. Then you can always put your own handles on. But it's more understandable for him - if it's one piece. Buy the right puzzle and have your husband put the handles on so it's more helpful.

Mrs. JJ: For Christmas I made a list out for what I wanted - it's usually if he gets toys for Christmas, they're never any good, anyway. I'll make a list of what he can use - where to get it. My husband's family is pretty good...

P.D.: It's a good idea - it's one I often give to parents - don't tell your best friends and grandmothers to buy what they think but buy what you know the child needs. And, if you know now the kinds of materials it's much more sensible. The kind of materials that you use and use are good solid stuff and they're expensive. So we might as well get gifts from other people.

P.D.: What about his relationship with you, your husband, with other children? Is there a change in that from 3 months ago to now?

Mrs. JJ: I think the relationship has changed between him and my husband. My husband really gets along pretty good now - the baby always

wanted my husband, the baby responds to him, the more that happens the more my husband plays with him. So they really get along good. He gives him time over the weekend... When I got the ice cream cone for him, my husband sat there for an hour watching him make a mess out of the ice cream. He sat there laughing, he said, 'You know this kid gets away with murder. When I was a kid, if I made a mess like that, I'd get killed.' I said: 'Be happy that he's making a mess.' But he was really thrilled about it. He sat there, J gave me a big smile.

P.D.: What about JJ's interest in other children?

Mrs. JJ: Well, he always had an interest, he always did get along with other children. That was the best time I had - friends over. If I had friends over with little children, he'd be very good. He'd just sit there and watch them play, they'd play with him. Now he even plays more with them.

P.D.: You mentioned to me that you were worried about when he goes home that there'd be a too long period of time when he'd be alone (not on program).

Mrs. JJ: That's what I'm afraid of. I figure when he gets home I'll be working with him as much as I can - I figure if I go out, I won't go anywhere, he goes with me. I figure if I can work his little exercises, it would be better for him and better for me. This way I won't get so nervous about it.

P.D.: Don't feel this kind of routine cuts out the pleasure in doing things together, because it doesn't. It's not going to be that critical if you do it at 2:00, if you do it at 5:00, or if you miss it. The other things he's going to be doing are important, too. Like that walk - this is learning, too - and JJ learns a lot with his eyes.

Mrs. JJ: There are a lot of stares. You get used to that.

P.D.: How do you feel about that?

Mrs. JJ: Sometimes it bothers me. It depends on the mood you're in. There was this one girl: she kept staring and staring - we were standing by some book store. She wouldn't take her eyes off of him so I got aggravated and said: Don't you hate the way some people stare at you! If they stare at you they stare at the baby. They're really terrible, because it's as though they never saw anything like that in their lives... sometimes it bothers me and sometimes it doesn't bother me at all. It depends on the way they're looking and how long they're looking. I know you have to expect some stares but some people get carried away with it... I think more young people are staring than older more mature people. This girl - who was a teenager -

P.D.: It wasn't very sensitive of her. Of all the people, you (would) expect them to recognize the problem. They are usually a little more compassionate (teenagers).

Mrs. JJ: I know someone in California, who is 9 years old and mentally retarded. Not physically handicapped. A man said something to him. The kid turned around and answered him funny. And the man said: "What's the matter with you? Are you stupid?" And the man really didn't know that this kid was mentally retarded. The kid said: "I'm mentally retarded. What's the matter with you!" When I saw the way that kid answered that man - that's the way I'd like to answer some of these people when they say... when they ask ignorant questions. "Well, he's got a problem. What's wrong with you?"... My biggest question from everybody is, it's not really a question, everybody tells me... when he's here, he's very stiff. But when he's home on weekends my mother-in-law... he's not stiff. Only with my father-in-law because he plays with him, holds him longer, but with other people he's not stiff. I don't know what's the big difference...

P.D.: Is there a difference when he starts playing? This is his pattern; this is how he reacts to excitement, by stiffening.

Mrs. JJ: He's either very floppy or very stiff. When he is in a rotten mood, forget about it.

P.D.: What's interesting to me is what you're really saying is you started out with the kind of hopes that were all physical. And what you've gotten... you haven't achieved the physical... but other things have become more important and apparent to you.

Mrs. JJ: You know when it was, I think... Everybody who saw him before, they kept telling me they didn't see any mental damage. So being they told me that, I just assumed that everything was all right and I never bothered... I thought there was nothing mentally wrong with him. I wanted help with physical problems. I see now he needs more mentally - not that he's retarded. I hope if I talk to him and make him understand more, he can help himself more physically because then he'll know what I want him to do.

P.D.: That's quite a switch... You're saying you never tried to stimulate one aspect of him because you didn't know that was necessary. ... Also children don't learn and don't just increase their mental capacity unless it's nurtured, too. And if you don't talk to them. So you first resolve not to go back to holding him (walking around washing dishes with him). It is a very good resolve because all you do is make it harder for you. And, it won't be helpful to JJ.

Mrs. JJ: Right.

P.D.: And I don't think he'd get as much satisfaction, really.

Mrs. JJ: I don't think he wants to be held that much anymore.

P.D.: I don't think so, either. You pointed that out beautifully in your first story, when you told me that when you thought that he wanted you and a book - that he didn't want you - he wanted the book. Our hopes

are that he wants the books and that he won't want you just to carry him around. He'll get more pleasure out of doing things with you than he would from being comforted (and held) like an infant.

Mrs. JJ: I don't think I have the energy to do it anymore. When I bring him back Sunday night, I come home with such a backache from carrying him from downstairs to up here. He keeps getting bigger now and I don't think I could do it any more.

P.D.: I think mothers have needs too. They need to know that they don't have to...

Mrs. JJ: Now I want him home. A few weeks ago, I didn't. I thought it was still too soon. He wasn't doing that good. If he's not doing good, he's going to come back to the same routine. I was working with him but I was still holding him too much. So now the last couple of weekends he sees I haven't been holding him, so he knows when he goes home...

P.D.: So you both are kind of ready for this (discharge) at this point. All right -- if you find by December 3rd you're getting back into the old situation... don't wait, call me -- if it's the week before (we had planned to admit him as an out-patient), we'll just take him the week before. But if you need that kind of support from us to help... I think it's good for him to be home and you settle him into a routine. We've discovered that it's good for most of the children. Now, in JJ's case it's going to be a question of your resolve (not to hold him like an infant). You have ability to do PT exercises, and you certainly know the kinds of things we do with him now... I have a lot of confidence in what you picked up here. If you find yourself getting back into this old (holding) kind of situation, give us a buzz and we'll bring him (back to out-patient infant school) faster, that's all.

Mrs. JJ: I try to be very strong. I had my mind set.

P.D.: I think you are, Mrs. JJ. I know why you're doing it. And I think it's not just a question of being stronger and resisting the child's crying. There's a purpose for it that's very good for JJ and very good for you and good for your husband... a demanding child is very hard for a family.

Mrs. JJ: He's not happy.

P.D.: He's not happy and you're not happy. So if you can have another kind of experience -- where he gets pleasure from you and you get pleasure from him, it's better for all of you. Without feeling guilty about it... you are the adult in the situation. He's a child. And sometimes, we kind of reverse roles and let the child dictate what happens.

Mrs. JJ: That's what happened.

P.D.: Well, that was anxiety and fear and not knowing what to do.

Mrs. JJ: That's too true.

P.D.: ... there are more things now that please him, more things that satisfy him. O.K. I'll see you tomorrow before you go.

Mrs. JJ: Thank you for everything.

P.D.: Don't thank me. I enjoy being with you. I'll see you tomorrow. I want to say good-bye. And besides, you're coming back. O.K.?